

# **Investigating the use of digital legacies with people affected by Motor Neurone Disease (MND): An Interpretative Phenomenological Analysis**

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for the degree of Doctor of Philosophy.

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## Declaration

This thesis is entirely my own work and has not been submitted, in full, or in part, for the award of a higher degree at any other educational institution. Sections of this thesis have been presented at conferences or disseminated via media outlets, details are presented below:

## Conferences

CLABBURN, O., 2015. Oral Presentation: To infinity and beyond: the use of a legacy generation app for people affected by motor neurone disease (MND) in the *Cutting Edge 2015- Answers to the Great Question, of Life, the Universe and Everything* at Edge Hill University, 18th April.

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EDGE HILL UNIVERSITY, 2016. *PhD student's family battle with Motor Neurone Disease inspires research to help others* [online]. 6 June. Available from: <https://www.edgehill.ac.uk/news/2016/06/16536/> [Accessed 20 November 2017].

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## **Preface**

My family first became aware of MND in the late-eighties when my Great-Aunt on my father's side was diagnosed with the disease. Shortly after her death, her twin-sister, my Dad's mother, was also diagnosed with MND. She died in 1993 after 18-months of living with the disease. It was later, during a family holiday in 1996, when my Dad first began to notice a weakness in his right arm and a subtle slurring of his speech. These symptoms were familiar to my parents due to the recent MND related bereavements. Subsequently, following a long period of extensive clinical testing, in 1997, he finally received an all too familiar diagnosis of MND.

Over the next three years, the disease gradually progressed which forced him to prematurely terminate his career in farm-animal management and husbandry (Clabburn, 1992). Gradually, he developed an increasing reliance on walking sticks, frames and wheelchairs due to the disease affecting his legs. One of his first symptoms was a slurring of speech meaning his bulbar function was quickly affected which made the use of Augmentative and Alternative Communication aids (AAC) essential for him to convey his thoughts, needs and concerns. During this three-year period, informal care was provided within the family home by my Mum, three brothers, and myself. As his condition worsened, he required increasing levels of care and support with daily tasks such as washing, dressing, toileting, eating, drinking and moving. Throughout this period, he would visit a local hospice where additional care was provided by day-centre staff and occasional respite stays. It became

evident during one of these respite stays, that the disease had progressed to such an extent whereby my Dad's care needs outweighed what we as a family could offer at home. Consequently, he moved into the Hospice on a permanent basis and received exceptional care for the final years of his life before passing away in April, 2004.

Clearly, knowledge of MND and the memory of my Dad was ever present in my mind in the years following his death. However, it was not until I was undertaking my undergraduate Educational Psychology degree where I began to channel and utilised my experience of being a young carer for my Dad. For my dissertation, I conducted a study investigating the experiences of young carers providing care for family members with MND, and, consequentially, bereavement (Clabburn and O'Brien, 2015). After graduation, I spent time working in a practical nature with young carers through facilitating regular support groups for young people to offer respite. This later progressed into supporting and advising the creation of a young carers' network in New Zealand. It was apparent throughout my work with young carers both in England and New Zealand, that young people who provide care for family members with terminal illnesses, face additional challenges to their non-terminal young carer counterparts. As such, I noted a lack of support available for young carers of palliative care patients who not only must contend with the provision of care and related stressors, but also worries, fears and concerns relating a known forthcoming bereavement of a family member.

I therefore began my PhD in the pursuit of alleviating some of the negative implications of being a young carer for a family member with MND, and,

ultimate bereavement. I began to draw upon my knowledge and experience of working with other young carers, whilst also considering the experiences I had obtained for my undergraduate dissertation project with young people specifically affected by MND. Crucially, however, I began to reflect on my personal experience of how I gained emotional support during the years of my Dad's illness, and also, following his death. This would occur through the listening and replaying of an answerphone message recorded by my Dad prior to his MND diagnosis. Part of the comfort this audio recording provided me during the time he was ill, was an ability to hear his voice and remember that he had not always sounded robotic in the form of his light-writer (Augmentative and Alternative Communication, AAC). The sound of his voice also promoted an element of reminiscence which would prompt happy memories of before he developed the disease. Furthermore, due to the answerphone being situated by the front door of the house, this inadvertent supportive resource was readily available for me to use when wanted, simply by pressing a button to play.

I also began to think about the various conversations regarding my Dad that I have had with my Mum and brothers since he has died. Due to being seven years old when he was diagnosed and his voice quickly deteriorating due to bulbar symptoms, I found myself seeking information and asking my family certain questions about my Dad, and specifically, his life before the disease.

Hence, the study is based on my personal reflection of a self-developed support method, combined with my experience of seeking information regarding my Dad following his death. Furthermore, my aim for the study is to elucidate the mutual benefits for both a plwMND creating a digital legacy, and, for a young person who watches and uses the legacy.

## **Abstract**

### *Background*

A video-based 'digital legacy' is a selection of videos which document a person's life, memories, achievements, or special family events. The videos are copied to a digital source to be specifically given to a child or young person to use in the future. A video-based digital legacy may either be purposefully recorded by the person living with MND (plwMND), or, compiled later by bereaved family members.

To date, there is little published research about how children and young people are affected when a family member has MND and subsequently dies. As such, there is a dearth of literature on how to best support these young people.

### *Objective*

This research is investigating the views, perceptions and experiences of digital legacies with people affected by MND.

### *Methods*

The study is underpinned by Interpretative Phenomenological Analysis (IPA) meaning a small homogeneous sample was required using purposive methods of recruitment. Interviews were conducted and audio recorded with four plwMND regarding their experiences of creating a purposeful digital legacy for a child or young person in their family. Interviews were also conducted with three bereaved young people regarding their experiences of using a video legacy of a parent who had died from MND. Also, a sample of twenty healthcare professionals, specialists and experts were interviewed from across the United Kingdom regarding their perceptions on the use of digital legacies with plwMND, and, young people who are bereaved.

### Ethics

Ethical approvals were obtained from a Faculty of Research Ethics Committee at Edge Hill University (FREC), the Health Research Authority (HRA), and the National Research Service for Scotland.

### Discussion

‘The Model of Reciprocal Bonds Formation’ and coining of the term ‘autobiographical chapter’ has been developed from this study. Creating a digital legacy provides a number of mutual challenges and benefits for both plwMND, and bereaved young people. Recommendations are provided regarding i) *optimal ‘windows of opportunity’ in which the digital legacy is recorded/used; ii) actionable solutions for current policy/practice; iii) future directions for research.*

### Key words

“Motor Neurone Disease”, “MND”, “Amyotrophic Lateral Sclerosis”, “ALS”, “digital legacy”, “bereavement”, “continuing bonds”, “interpretative phenomenological analysis”, “end of life care”.

# Chapter 1 - Introduction

“The beginning of wisdom is the definition of terms.”

Socrates (470-399 B.C.)

The purpose of this introductory chapter is to provide background and contextual information about motor neurone disease (MND). An overview of the disease will be provided along with a brief explanation of how the disease affects people physically and psychologically.

## 1.0 - Background to MND

First described in 1874 by Jean-Martin Charcot, motor neurone disease (MND) remains a rapidly progressive neurodegenerative disease with no known cure (O'Brien and Clabburn, 2016). MND is often used as an umbrella term to refer to a collection of disease types which all result in the degeneration of motor neurones. There are four main types of the disease; Amyotrophic Lateral Sclerosis (ALS), Progressive Bulbar Palsy (PBP), Progressive Muscular Atrophy (PMA) and Primary Lateral Sclerosis (PLS). Due to being the most commonly occurring type of motor neurone disease, ALS is often used as a synonymous term, particularly in North America and parts of Europe (Tiryaki and Horak, 2016).



MND is relatively rare with approximately six new people being diagnosed with the disease every day in the UK which results in around 5000 being affected by MND at any one time (MND Association, 2017a). The incidence of the disease seems to be more common in men than women (1:350, 1:472 respectively), with the highest incidence in 55 to 75 year olds (Hobson et al., 2016). This raises concerns around a potential rise in MND cases due to the increase in life of expectancy across the general population (Talbot and Marsden, 2008). However, while age onset is generally over 50, a significant proportion (10%) of individuals will develop the illness before 45 years of age and are often referred to as having 'young-onset' MND (Turner et al., 2012). This suggests that a number of people living with MND (plwMND), may have young children resulting in young people having to care and grieve for a terminally ill family member with MND.

The disease occurs sporadically in 90-95% of cases with some speculation that exposure to certain pesticides, fertilisers, heavy metals and physical trauma as contributing factors (Bozzoni et al., 2016). While the biomedical cause of MND is still unknown, scientific research is beginning to better understand the potential contributing factors culminating in the onset of symptoms (Tiryaki and Horak, 2016). MND is noncontagious, but a genetic cause has been identified for a small proportion of the 5-10% of cases with a family history of the disease known as familial MND (Greenway et al., 2006; Renton, Chio and Traynor, 2014; Rafiq, 2016).

At this stage, such causal factors are tentative at best with older-age and genetic inheritance being the strongest indicators to developing MND. Although there is no cure for MND, specialised drugs such as Riluzole<sup>®</sup> have been developed to slow down symptom progression (Miller, Mitchell and Moore, 2012), with others such as Edavarone<sup>®</sup> currently in development (The Writing Group on behalf of the Edaravone, 2017). Consequently, MND is often considered to be a 'death sentence' with 50% of plwMND dying within 30 months of symptom onset (Locock, Ziebland and Dumelow, 2009; Kiernan et al., 2011).

A key aspect of MND is that cognitive abilities and senses often remain intact whilst the individual becomes trapped in their rapidly deteriorating body (Locock, Ziebland and Dumelow, 2009). In addition to physical deterioration, cognitive impairment has also been associated with the disease with approximately 50% of plwMND experiencing some cognitive change, often with symptoms that are commonly related to damage or dysfunction in the frontal lobe (Goldstein and Abrahams, 2013). Emotional lability is a fairly common cognitive impairment which can impact on empathy skills resulting in problems with general family life (Gibbons et al., 2008; Hobson et al., 2016). Frontotemporal Dementia (FTD) is also a common neurobehavioral symptom of MND which can result in subtle to serious cognitive impairment (Oliver, 2002; Merrilees et al., 2010).

An additional area of concern for plwMND is a sense of feeling 'locked in' due to *dyspharia* (Locock and Brown, 2010). This decline in verbal communication occurs in 70-80% of MND cases resulting in high reports of social isolation (Oliver and Borasio, 2004; Whitehead et al., 2011). A means of decreasing

social isolation through enabling communication is with the use of high technology devices such as light-writers and 'text to speech' programmes (Leigh et al., 2003). Users are also able to tailor the speech produced by such AAC programmes through engaging in a process of 'voice banking'. If this is carried out prior to significant vocal decline, the plwMND can have a voice for use with AAC which combines their own voice recordings with a synthetic 'donor' voice (Beukelman, Fager and Nordness, 2011). In contrast to voice banking where users create and 'speak' unique sentences and messages, an alternative is 'message banking' where fixed sentences or phrases are recorded for future use (Costello, 2014). The AAC device can then be adapted to include switches or eye-tracking when physical conditions worsen to provide a method of verbal communication for those with dysphasia (Beukelman et al., 2007).

Due to constant disease progression and physical decline often at a rapid rate, plwMND will have increasingly challenging and unremitting caring needs. Assistance will usually be required in a variety of contexts; feeding, toileting, dressing, mobility, communicating and translating, amongst many more daily tasks that will, in time, become impossible (Oh and Kim, 2017). As summarised below in Figure 1, treatment becomes symptomatic in assisting with various physical aspects of care and managing respiratory difficulties, pain and dietary concerns (Oliver, 2002). This emphasises the need for appropriate multidisciplinary care for plwMND from a range of allied health professions which is additionally linked to prolonged survival (Traynor et al., 2003; Simon et al., 2015).

Figure 1- A summary of the four key areas of palliative care for plwMND (Oliver, 2002)

<b><u>Physical Care:</u></b> <i>Symptom Management</i>	<ul style="list-style-type: none"> <li>•Pain management</li> <li>•Feeding &amp; personal care</li> <li>•Respiratory assistance</li> <li>•Communication assistance</li> </ul>
<b><u>Social Care:</u></b> <i>Effects on family &amp; carers</i>	<ul style="list-style-type: none"> <li>•Fear of diagnosis &amp; dying</li> <li>•Communication Issues</li> <li>•Shift in parenting &amp; family roles</li> </ul>
<b><u>Psychological Care:</u></b> <i>Effects on the patient</i>	<ul style="list-style-type: none"> <li>•Fear of diagnosis, dependency &amp; dying</li> <li>•Reduced social life</li> <li>•Depression and anxiety</li> </ul>
<b><u>Spiritual Care:</u></b> <i>existential concerns &amp; meaning of life</i>	<ul style="list-style-type: none"> <li>•Religion</li> <li>•Past, current and future identity</li> <li>•Euthanasia</li> <li>•Self-transcendence</li> </ul>

Ultimately, palliative care is crucial to promote quality of life (QoL) for both plwMND and their families (Oh and Kim, 2017). This means that the support provided aims to enhance psychological, social and existential well-being, with less focus upon the inevitable and progressive decline of physical abilities (Foley, Timonen and Hardiman, 2012). It has therefore been suggested that plwMND adopt new existential outlooks on life, and find alternative ways to attribute meaning to their illness (Fanos et al., 2008). This is reinforced by the significant relationships which exist in their life, and by continuing to feel valued and useful to others, despite becoming increasingly reliant on others as their physical condition worsens (Vitale and Genge, 2007; Pagnini, 2013). Hope and purpose therefore becomes redefined for plwMND through setting achievable goals in accordance with their physical capabilities (McLeod and

Clarke, 2007; Fanos et al., 2008). Yet, adopting this outlook can be challenging due to being forced to discard future life plans, long-term ambitions, or, being unable to watch children and grandchildren reach adulthood (Bolmsjo, 2001; Fanos et al., 2008; Pagnini, 2013).

Depression and anxiety have consequently been suggested as inevitable symptoms for plwMND (Averill, Kasarkis and Segerstrom, 2007). Severity of the psychological impact of MND has been associated with the stage and severity of disease development (Real et al., 2014), limb function impairment (Goldstein et al., 1998), and loss of independence (Felgoise et al., 2010). However, a literature review conducted by McLeod and Clarke (2007) highlight there to be a 'virtual absence' of depression affecting between 11% and 15% of plwMND (p.6). It has instead been suggested that psychological symptoms are often linked with negative perceptions of the illness, and, being forced to limit and restrict recreational activities due to disease constraints (Goldstein et al., 1998; Felgoise et al., 2010). Yet, due to the rise in recent years of devices such as smartphones, tablets and computers, there is suggestion that use of technology may alleviate some of these psychological symptoms (O'Brien and Clark, 2008).

## **1.1 - Rationale**

This chapter has provided contextual information regarding MND and highlighted a plethora of physical and psychological implications for plwMND. Poignantly, it has been emphasised that plwMND are often faced with an 'existential shock' (Brown, 2003, p.210). The existing literature suggests

plwMND often feel as though life becomes without purpose and meaning as their physical condition worsens (Albert et al., 2005). Despite this, there is limited knowledge regarding how to best support plwMND with such existential concerns when physical capabilities are restrictive and constantly declining. Furthermore, these feelings are exasperated through acknowledging that the disease and imminent death will result in limited opportunities to be involved and contribute to the lives of children and young people within their family.

The World Health Organisation now recognise that palliative care should encompass the whole family, not simply the needs of the patient (WHO, 2017). However, there remains little published research addressing the experiences of bereaved carers, after caring for a person with MND, or the use of interventions to ease the transition from caring to bereavement for children and young people.

Additionally, NICE guidelines state that plwMND should be assessed by healthcare professionals '*regularly and include consideration of activities of daily living, the home environment and the need for technology*' (Oliver, 2016, p.145). As such, these professionals play a significant role in signposting and supporting plwMND with use of technological equipment. Yet providing optimal support and care is often challenging due to there being few interventions, with documented effectiveness, which healthcare professionals can use to underpin daily practice (Beukelman et al., 2007). Furthermore, little is currently known about healthcare professionals perceptions of the use of emerging

technologies used to support plwMND to continue to be involved in the lives of young people in their families, not only as their condition deteriorates, but also, following their death.

## **1.2 - Research aim, question and objectives**

This thesis aims to investigate the views and experiences of creating/using a digital legacy with people affected by MND. This is the idea that plwMND record a selection of videos, specifically for a child or young person in their family, to use following their death.

### **Research question**

The research question which underpinned the study was: 'What are the views, experiences and perceptions of digital legacies with people affected by MND?

This question was driven by three distinct research objectives:

**Research objective 1:** Investigate the feasibility, experiences and perceived value of plwMND in creating a digital legacy for a child or young person in their family.

**Research objective 2:** Investigate the views and experiences of bereaved young people (aged 11-24) using a digital legacy created by or featuring a family member who had MND.

**Research objective 3:** Investigate healthcare professional, specialist and expert perceptions of the benefits, value, appropriateness, barriers and challenges of digital legacies by people affected by MND.

In order to explore the existing research base in accordance with the research aims, two structured narrative reviews were conducted. The next chapter (Chapter 2), will begin by providing an overview of the methods adopted to review the literature. Following this, a narrative review of existing literature will be provided in Chapter 2 which focusses upon people with a terminal illness reflecting upon their life and creating a legacy. Similarly, Chapter 3 will provide a review of literature centred upon how bereaved children and young people continue bonds with the deceased. To ensure clarity throughout this thesis, 'young people' will be used as an encompassing term for infants, children and adolescents.



## Chapter 2 - Literature Review

“One lives in the hope of becoming a memory.”

Antonio Porchia (1886-1968)

The previous chapter (Chapter 1) has provided background information regarding MND and described the physical and psychological effects of living with the disease. This chapter is the first of two systematically conducted narrative reviews and will begin with a brief description of the literature search process. The narrative review will then follow which focuses upon interventions which encourage people with a terminal illness to reflect upon their life and create a legacy.




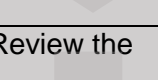
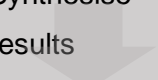

### 2.0 - Review design

The purpose of conducting the literature review is to provide an up-to-date understanding of existing literature and highlight significant gaps in the current knowledge (Gray, 2014; Boland, Cherry and Dickson, 2014). Importantly, however, reviewing the existing literature provided a ‘*foundation and inspiration*’ which informed and shaped the development of the current study (Boote and Beile, 2005). A narrative review was identified as an appropriate way to provide an overview of current research regarding the current study

(Bryman, 2012). This provides a flexible approach to present an integrated and synthesised interpretation of both qualitative and quantitative evidence relating to the current study (Mays, Pope and Popay, 2005). It was therefore necessary to develop “*a systematic and explicit method for identifying, evaluating and synthesising the existing body of completed and recorded work produced by researchers, scholars, and practitioners*” (Fink, 2014, p.3).

In keeping with the study aims outlined in the previous chapter (Chapter 1), two literature reviews were conducted in accordance with the ‘seven steps’ outlined by Fink (2014). An overview of each step is provided below in Table 1, along with application to the current study.

Table 1- An overview of the 'seven steps' to reviewing literature (Fink, 2014).

Seven steps (Fink, 2014)	Purpose/aim	Application/adherence within the study
1. Develop research questions 	<i>Create and refine specific questions</i>	<ul style="list-style-type: none"> <li>Two questions were developed in accordance with the context of the study;               <ul style="list-style-type: none"> <li>i) What are the interventions, and potential benefits, for people with a terminal illness to create a legacy?</li> <li>ii) How do bereaved young people continue bonds with the deceased?</li> </ul> </li> </ul>
2. Select appropriate bibliographic databases	<i>Identify databases most appropriate for the research topic</i>	<ul style="list-style-type: none"> <li>Searches were standardised using six databases (CINAHL, Medline, EMBASE, PsychINFO, PubMed and BNI). Databases selected due to context of the review questions</li> <li>Supplementary hand-searching of articles through screening reference lists</li> </ul>
3. Choose relevant search terms 	<i>Extract key words to build search terms specific for the research question</i>	<ul style="list-style-type: none"> <li>Key words identified for each review question</li> <li>Synonyms and related terms considered.</li> <li>Truncation (*) used to capture spelling variations &amp; Boolean ('AND'/ 'OR') to combine search terms</li> </ul>
4. Apply practical screening criteria 	<i>Identify a broad range of articles which cover the topic of interest</i>	<ul style="list-style-type: none"> <li>Article title/abstract screened for relevance using the inclusion and exclusion criteria</li> <li>Duplicates removed</li> <li>Publication year parameters (see Figure 2 and 3)</li> </ul>
5. Apply methodological screening criteria 	<i>Screen the quality of articles and narrow down the search for the best available studies</i>	<ul style="list-style-type: none"> <li>Any study design (qualitative and quantitative)</li> <li>Peer reviewed journal articles only (excl. conference proceedings, errata, unpublished dissertations/thesis) (see Figure 2 and 3)</li> </ul>
6. Review the literature 	<i>Assess the quality, validity and reliability of each identified article</i>	<ul style="list-style-type: none"> <li>Full text screen</li> <li>Articles reviewed using the Joanna Briggs Institute (JBI) Critical Appraisal Tools (2017)</li> <li>Summarised into a review table (see appendix 1 and 2)</li> </ul>
7. Synthesise the results 	<i>Describe, synthesise and evaluate the status of current knowledge regarding the research topic</i>	<ul style="list-style-type: none"> <li>Chapter 2: What are the interventions, and potential benefits, for people with a terminal illness to create a legacy?</li> <li>Chapter 3: How do bereaved young people continue bonds with the deceased?</li> </ul>

### 2.0.1 - Literature search method

As outlined in Table 1, two literature reviews were undertaken and standardised using the same six databases; CINAHL, Medline, EMBASE, PsychINFO, PubMed and BNI. These databases were chosen due to the breadth of cross disciplinary coverage across national, and international, peer-reviewed journals.

Individual search strategies were developed for each of the two reviews using broad search terms to ensure a comprehensive search. Synonyms and related terms were considered and searched using the Boolean 'OR' (e.g. "legacy" OR "memoir"). Truncation (\*) was utilised to capture spelling variants (e.g. reminiscence therap\* would capture "reminiscence therapy" and also "reminiscence therapies"). The different concepts were combined by the use of the Boolean 'AND'.

The title and abstract of each 'hit' generated from the searches, was then screened for relevance against the inclusion/exclusion criteria for that review.

Additional articles were located through hand searching the reference lists of papers which met the inclusion criteria. All articles were then critically appraised to assess methodological quality (Fink, 2014). There is currently no definitive approach in critical appraisal and integration of findings from studies which have adopted varied methodological approaches (Walshe et al., 2009).

Therefore, all articles which met the inclusion criteria were critically appraised and assessed for methodological quality using the Joanna Briggs Institute (JBI) Critical Appraisal Tools (JBI, 2017). These tools were recognised as appropriate due to providing a series of 'critical checklists' to be completed dependent upon various study designs and methodologies. There were six JBI checklists used during the assessment of literature; randomised controlled trials (13 items), literature reviews and syntheses (11 items), qualitative (10 items), quasi-experimental (9 items), case report (8 items), and lastly, text and opinion (6 items). However, the checklists do not include a facility to score the quality of papers. It was therefore deemed appropriate to adapt the checklists and create a numerical indicator of quality for all articles reviewed. In response to the prompts provided within the JBI checklists, each 'yes' was awarded a score of one. Due to identifying small numbers of appropriate articles, along with wide spread low quality, a decision was made not to exclude articles based on quality appraisal alone. Instead, any prompts/questions within the JBI checklist which were not met by the article, have been utilised within the narrative review to highlight additional study limitations in the support of critique.

As such, the critical appraisal process for both literature reviews was standardised using the same collection of JBI critical appraisal tools (Booth, Papaioannou and Sutton, 2012). Finally, in accordance with narrative review guidance, all articles which were included in the narrative reviews were

synopsised into 'article review tables' which include a numerical indicator of quality (see appendix 1 and 2) (Green, Johnson and Adams, 2001; Booth, Papaioannou and Sutton, 2012).

### 2.0.2 - Section summary

The purpose of this first section of the chapter, has been to provide a broad overview of the literature review process adopted for the thesis. The following section will be the first of two narrative reviews which were conducted.

## **2.1 - Literature review one**

This section of the chapter will present a narrative review of the various interventions which encourage people with a terminal illness to reflect upon life and create a legacy.

### 2.1.0 - Background

The concept of a 'legacy' refers to '*what a person leaves behind – how a person will be remembered and what they will be remembered for (good and bad)*' (Breitbart, 2016, p.1). Accordingly, the concept of building or creating a specific legacy to be passed on to family members and loved ones within the context of palliative care, has in recent times gained an increasing prominence in the literature (Chochinov et al., 2005; Ando et al., 2010; Vukashovic et al., 2016). Foster et al. (2012) suggest that a legacy, within this end of life (EoL)

context, is a broad venture and defined as *“doing or saying something that is remembered, including both intentional and serendipitous legacies”* (p.573). Moreover, Allen et al. (2008) suggest that a legacy not only provides a resource to be used and enjoyed by family members following the patient’s death, but also, enables the terminally ill individual to attribute meaning to their life through creating a tangible legacy resource. With this in mind, specially created legacies, in the palliative care context, can be mutually beneficial for both the patient and bereaved family, friends or loved ones (McNees, 2009). However, few studies have specifically explored healthcare professionals’ perceptions of legacy generation within palliative care contexts. Notably, a systematic review published by Martinez (2017) only identified two articles which had reported healthcare professionals’ perceptions of creating legacy through an intervention called dignity therapy. One of these studies, conducted by Chochinov et al. (2012), collected data with both patients and healthcare professionals. It was reported by staff that the legacy had a positive effect on their provision of care due to being able to learn about the patient’s past, and their future wishes and goals. Only one study to date has specifically investigated the perceptions of hospice staff regarding patients creating a legacy from dignity therapy. Montross et al. (2013) report how hospice staff experienced a sense of increased connection with patients upon learning about their life and history through creating a legacy. In turn, this had a direct impact upon staff who gained an increased sense of job satisfaction and fulfilment of their caring role. Moreover, with the ability for legacies to be created in a variety of forms such as oral histories or written biographies, building it can be an individualistic process dependent on personal preference

and potential illness-related barriers. Yet, both of these studies focused specifically on the creation of a written legacy, as shaped and structured by dignity therapy. Consequently, there is a dearth in the literature regarding healthcare professionals' perceptions of digital legacies within the context of palliative care, and more specifically, for plwMND.

It has been argued that creating a legacy alleviates existential distress for people approaching death due to the theory of 'symbolic immortality' (Rosenbaum et al., 2006). In his theory, Lifton (1979) postulates that people often experience a sense of anxiety when confronted with their own mortality. He noted that we, as people, often try to deny and repress the reality of our death, yet, deep inside, we know that we are going to die (Drolet, 1990). This 'middle knowledge', manifests as a fundamental need to create and preserve 'symbols' which will ensure our 'immortality' once we have died (Lifton, 1979). He suggested there to be five main ways in which symbolic immortality may be achieved:

- *Theological immortality*: possessing a belief in life after death (e.g. "I will be going to heaven")
- *Immortality of nature*: becoming eternalised through becoming at one with nature and the ongoing cycles of life and death (e.g. "I will be the wind that blows you")
- *Experiential/spiritual immortality*: 'going beyond' the limits of normal life and achieving a sense of transcendence (e.g. "I will be remembered for my ballet and dance" / "you will always feel me around you")



- *Creative immortality*: having a lasting influence on other people through the things we have made (art, poetry, academia etc.) or benevolent actions (teachers, nurses, empathic friend etc.) (e.g. “I will live on through my artwork and the students I have taught to paint)
- *Biological/physical immortality*: our thoughts, values and memories are transferred to our children and future generations through our DNA (e.g. “I will live on through my children”)

It is therefore argued by Rosenbaum et al. (2006) that creating a legacy provides symbolic immortality for people approaching the end of life through the biological and creative domains. The legacy will contain information that the person wishes their family to know about their life and memories (biological immortality), whilst it has also been carefully tailored and constructed by themselves (*creative immortality*).

To date, there is limited research which has investigated the concept of legacies being created by plwMND. However, two studies have investigated the feasibility of dignity therapy within the context of MND. Bentley et al. (2014), and Aoun, Chochinov and Kristjanson (2014), both carried out studies in Australia with samples of 29 and 27 plwMND respectively. Individually, each study collected a number of quantitative baseline measures using well validated scales such as the Herth Hope Index (HHI) (Herth, 1991), Patient Dignity Inventory (PDI) (Chochinov et al., 2008), ALS-Assessment Questionnaire-5 (ALSAQ-5) (Jenkinson et al., 2007), and, the Spiritual well-being subscale of Functional Assessment of Chronic Illness Therapy Scale

(FACIT-Sp) (Peterman et al., 2002). These measures were later re-administered following completion of the dignity therapy intervention. Findings reported by Bentley et al. (2014) suggested that no significant changes in hope, dignity or spirituality were detected at group level following the intervention. However, findings generated from a participant feedback questionnaire suggested that; participants found it personally helpful (89.2%,  $n=26$ ), helpful to their family (85.2%,  $n=25$ ), promoted role preservation (60.8%,  $n=18$ ), reduced sense of burden (28.6%,  $n=8$ ) and enabled a feeling of closeness to those who were important to them (70%,  $n=20$ ).

Similarly, Aoun, Chochinov and Kristjanson (2014) elucidate that whilst findings from this population are similar to dignity therapy studies carried out with cancer patient populations, a number of unique considerations must also be taken into account for plwMND. Chiefly, due to physical deterioration, dignity therapy must be offered early on in the disease trajectory whilst the patient is able to speak. Furthermore, additional time was required by some participants who communicated through the use of augmentative and alternative communication devices (AAC), email, or, through support from their spouse. Consequently, Aoun, Chochinov and Kristjanson (2014) suggest that whilst dignity therapy may seemingly endorse a number of psychological benefits for plwMND, the intervention may require a streamlined process or method for efficient implementation. Such findings regarding the intervention being financially costly and time rich were similarly reinforced in a number of literature reviews and highlighted as key limitations of dignity therapy (Donato et al., 2016; Bentley et al., 2017; Martinez et al., 2017).

With this in mind, it is suggested that creating a legacy may generate a number of benefits for plwMND. However, with the exception of these two studies, to date, there is a dearth of published research regarding the creation of legacies by plwMND. As such, it was necessary to conduct a broader search of literature across alternative terminal illnesses in order to answer the question; *What are the interventions, and potential benefits, for people with a terminal illness to create a legacy?*

#### 2.1.1 - Search method

In accordance with the literature search method outlined earlier in this chapter (pages 12-15), the following key words ["legacy" OR "legacies" OR "memoir" OR "memory making" OR "reminiscence therap\*" OR "life review" OR "life-review" OR "life stor\*" OR "dignity therapy" OR "video\*" OR "digital memor\*"] AND ["end of life" OR "EOL" OR "palliative" OR "terminal\*" OR "hospice" OR "MND" OR "motor neuron\* disease" OR "ALS" OR "amyotrophic lateral sclerosis" OR "Lou Gherig's"] were searched within article titles.

#### 2.1.2 - Inclusion/exclusion criteria

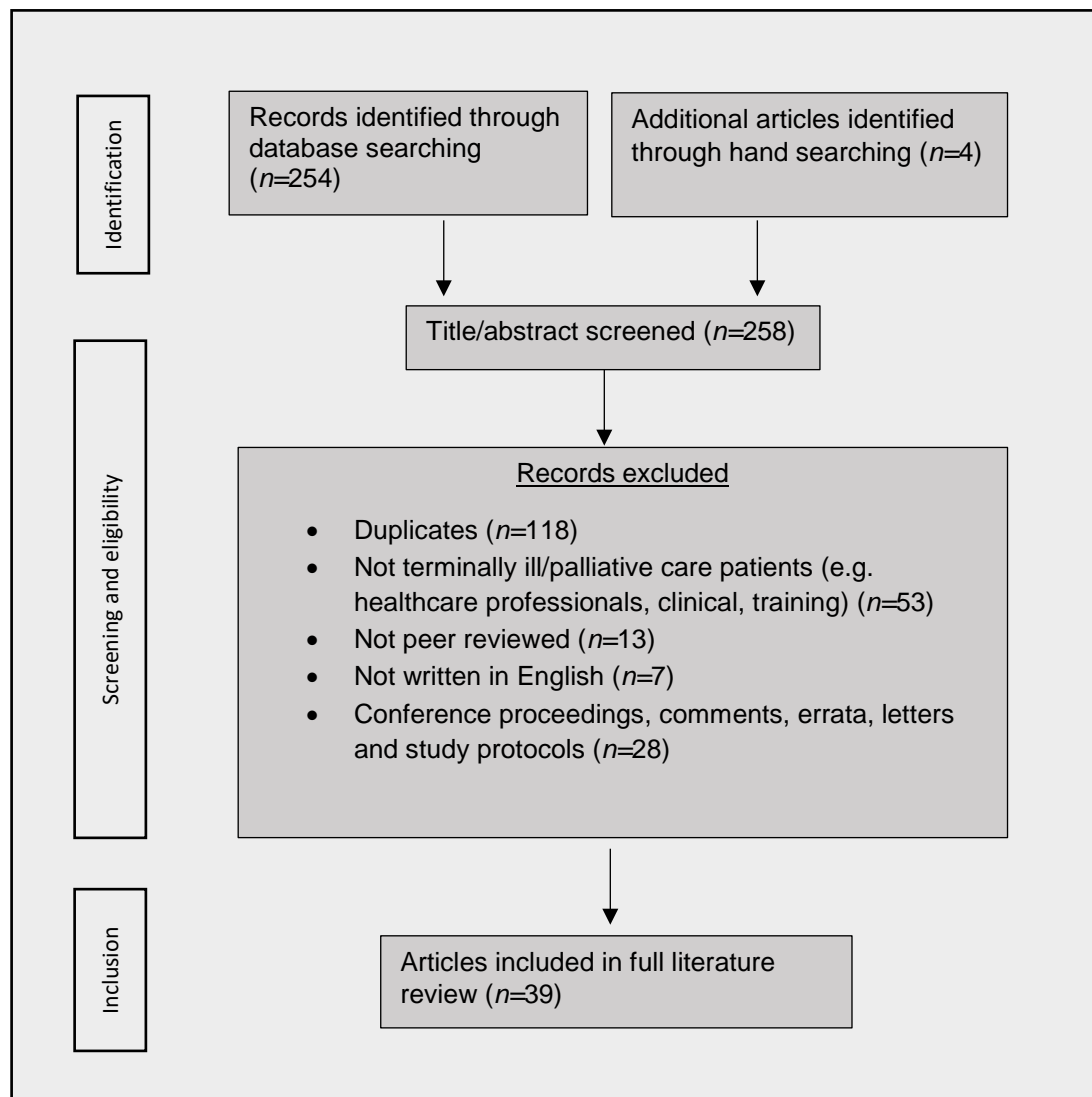
Dates for inclusion of articles were limited from 1993 to 2017 in accordance with the first paper utilising therapeutic life review in palliative care populations being published (Lichter, Mooney and Boyd, 1993). Unpublished dissertations, theses, or non-peer-reviewed articles were excluded. Language limiters were applied for articles published in English. All study designs and both quantitative and qualitative methodologies were included. Finally, articles

which had not focused on adult populations with a terminal illness or receiving palliative care were omitted. The majority of these articles were directed towards healthcare professionals and intended to be used for training or educational purposes.

### 2.1.3 - Search results

A summary of the search results is provided below in Figure 2. In total, 258 hits were returned with the majority being ruled out due to duplication (n=118) or having focus on training needs or guidance for allied health professionals (n=53). Following scrutiny of the remaining article titles and abstracts, 39 met the inclusion criteria for the review. Articles were then reviewed in accordance with the process described earlier in this chapter (pages 12-15). A summary of all included papers and respective indicator of quality score is provided for clarity (see appendix 1). Articles were then synthesised into three over-arching themes of; *therapeutic life review*, *dignity therapy*, and finally, *alternative legacy activities*. Each of these themes will be discussed in turn with contextual information provided for each intervention.

Figure 2- A summary of search results



## 2.2 - Therapeutic life review

The concept of 'life review' was coined by Butler as a normal psychological process whereby people approaching the end of their life often reflect and reminisce on their life, memories and achievements (Butler, 1963). He noted that often this was a spontaneous process whereby older people evaluate their life and engage in a crucial task of 'making sense of the life they have lived' (Butler, 2002; p.1). This process of reminiscence frequently occurs in older

people through increased recollection of memories, daydreaming, storytelling and amplification of nostalgia (Haber, 2006). As such, therapeutic life-review attempts to further this process of recollection through encouraging participants to engage in an evaluative activity (Keall, Clayton and Butow, 2015). A variety of therapeutic life review frameworks and guides have been developed to facilitate this process (Lewis and Butler, 1974; Birren and Deutchman, 1991; Haight and Webster, 1995). Whilst many of these frameworks differ in their approach, each have the ubiquitous aim of resolving past conflicts, atonement for historical actions, and reviewing the past in order to understand the present (Butler, 2002).

The intervention can be carried out independently, or as part of a group with guidance from a facilitator (Haber, 2006). Often stimuli such as such as photo albums, music, scents and scrapbooks are commonly used to evoke life memories (McNees, 2009). This encourages participants to evaluate the meaning attributed to the specific events that are recalled (Keall, Clayton and Butow, 2015). Normally the life review will consist of an oral history, however, through use of audio-recording equipment and later transcription, written reviews are also possible (Haber, 2006). Regardless of the format, the process of evaluating life and memories is perceived to promote life satisfaction, enable an understanding of the present- and, ultimately, prepare the person for death (Butler, 2002).

The initial concept of reminiscence and life review originated in observations from older people (Butler, 1963). However, there have since been assertions that this spontaneous recollective activity is often stimulated by a major crisis such as the confrontation of impending death (Butler, 2002). Subsequently, the transferral of life review from aged populations to palliative care patients, has since gained increased presence in literature (Ando, Tsuda and Morita, 2007; Keall, Clayton and Butow, 2015).

#### 2.2.1 - Psychological benefits of therapeutic life review

A number of the articles identified had investigated the use of therapeutic life review in palliative care and end of life contexts (Haber, 2006; Ando, Tsuda and Morita, 2007; Ando et al., 2008; Ando et al., 2009; Ando et al., 2012; Keall, Clayton and Butow, 2015; Kwan, Ng and Chan, 2017; Wang, Chow and Chan, 2017). One systematic literature review, which was recognised to be of high quality according to the JBI checklists, was conducted by Keall, Clayton and Butow (2015). This review sourced articles from six databases. The majority of the 1776 articles identified during a scoping search were rejected due to not being focused upon palliative care contexts. A total of 14 articles were included in the review which featured research samples from USA ( $n=5$ ), Japan ( $n=3$ ), Canada ( $n=2$ ), Australia ( $n=1$ ), Hong Kong ( $n=1$ ). Additionally, two of the articles involved cross-cohort participants from Canada and Australia, and Canada, Australia and America combined. Keall, Clayton and Butow (2015) note that the small number of articles included in the systematic review exemplifies the early stage of development for life review in palliative care contexts. The authors also report the majority of reviewed articles being

underpowered due to attrition as a result of participants dying prior to study completion. As such, therapeutic life review interventions which were shorter in duration had lower attrition rates which tended to highlight increased efficacy of the intervention. Moreover, nine out of the ten interventions investigated in the articles, were facilitated by a psychologist, psychiatrist, or social worker, thus raising the cost of intervention delivery. Regardless of these limitations, significant improvements were noted in patient depression, spiritual wellbeing, distress, suffering, and happiness. However, whilst this systematic review was rigorously conducted with adherence to appropriate review protocols, the 14 papers reviewed were limited to only those available in English. This is pertinent as a number of researchers investigating therapeutic life review in palliative care are based in China (Chen et al., 2016; Kwan, Ng and Chan, 2017; Wang, Chow and Chan, 2017). This highlights the potentiality of articles providing key information on life review in palliative care context being omitted due to being published in Chinese alone.

Poignantly, another systematic review, which was noted to be of good quality based upon the JBI quality indicator, was conducted by Chen et al. (2016). The authors broadened searches to include both English and Chinese publications before pooling data. In total, 2943 articles were identified during scoping searches through seven databases. Eleven articles were included in the review, of which nine were randomised controlled trials meaning the authors were able to combine a sample of 575 participants in specific domains. Many of these papers had methodological inconsistencies making a meta-analysis on some factors challenging (Chen et al. 2016). However, pooled data



for 251 participants, from four studies, suggested significant improvements in quality of life for patients after a life review intervention (SMD=2.21, 95% CI (1.58, 2.83),  $p<0.00001$ ). Additionally, pooled data from two randomised controlled trials and two clinical controlled trials created a sample size of 101 participants. Analysis of this data demonstrated that therapeutic life review improved depressive symptoms and increased self-esteem (MD=3.33, 95% CI (0.16, 6.50),  $p=0.004$ ).

Additional benefits of therapeutic life review for 12 terminally ill cancer patients have been postulated by Ando, Tsuda and Morita (2007). Outcome measures for spiritual wellbeing were assessed using the Skalen zur Erfassung von Lebens qualitat bei Tumorkranken- Modified version (SELT-M) (van Wegberg et al., 1998) due to the scale being translated and validated in Japanese. The researchers suggest that therapeutic life review was an effective way for the participants to find meaning in their lives and displayed significant increases in spiritual wellbeing, according to the SELT-M, after participants received the life review intervention. Ando et al. (2008) later developed a short term life review (STLR) based on a one week time frame. The efficacy of this abridged version was assessed with a larger sample of 30 participants diagnosed with terminal cancer, recruited from two general hospitals in Japan. The STLR consists of two sessions; the first involves an audio-recorded life review conducted by the facilitator. This is then compiled by the facilitator into a legacy document and given to the participant at the beginning of the second session to stimulate discussion. This document was often in the form of an album or scrapbook including photographs representing the frequently occurring

concepts, feelings and words mentioned by the patient in the previous interview. Pre and post measures were issued to participants in the form of the Functional Assessment Chronic Illness Therapy-Spiritual (FACIT-Sp) (Peterman et al., 2002) and the Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). Whilst this paper achieved a high indicator of quality based upon the JBI checklists, study limitations were also evident. Most notably in the predominantly older ( $n=74$  years), and female sample ( $n=22$ ). Regardless of this, the authors document a number of positive outcomes from the intervention in a variety of psychological domains. Following the STLR, significant decreases were noted in anxiety ( $Z = -3.8, p= 0.001$ ), depression ( $Z= -3.7, p= 0.001$ ), suffering ( $Z= -3.5, p= 0.001$ ), and, total HADS scores ( $Z= -4.1, p<0.001$ ). Additionally, the scores from baseline FACIT-Sp measures significantly increased after the STLR ( $Z= -4.2, p=0.001$ ), suggesting the therapeutic life review to be beneficial for spiritual wellbeing. Furthermore, participants were able to reaffirm life roles through engagement with the intervention. Of importance, however, is that the intervention had a short timeframe in order to maximise the benefit for participants experiencing rapid illness progression (Ando et al., 2008), with suggestion of two weeks being optimal (Kwan, Ng and Chan, 2017).

### **2.3 - Dignity therapy**

Whilst therapeutic life review interventions encourage participants to reminisce on life and evaluate memories, an alternative reminiscence therapy is that of dignity therapy. The concepts of 'respect, autonomy, empowerment and communication' are often identified as crucial areas of consideration in order

to promote dignity in patients receiving palliative care (Kennedy, 2016, p.45). Loss of independence, symptom distress and perceived self-image are just a few aspects of terminal illness which affect a person's dignity (Enes, 2003). Yet Chochinov et al. (2002) noted that the term 'dignity' was broadly used in a variety of contexts and often applied to issues surrounding euthanasia and assisted suicide. The 'dignity conserving care model' was consequently developed by Chochinov et al. (2002) through interviewing 50 terminally ill patients to ascertain what dignity meant to them. Based on this model, Chochinov et al. (2005) developed 'dignity therapy', a brief psychotherapeutic intervention for end of life patients which strives to bolster dignity, meaning and purpose in their final days. Similar to therapeutic life review, dignity therapy provides an opportunity for people at the end of life to reflect on their personal accomplishments, memories and future wishes for their loved ones. These reflections are then recorded through the production of a 'generativity document', meaning something that will live on once the patient has died (Montross et al., 2013).

Dignity therapy generally consists of three to four visits from a trained dignity therapist to a patient. The sessions provide an opportunity for the terminally ill person to discuss the issues that matter most to them and highlight specific memories or experiences that they wish to be remembered for once they have died (Aoun, Chochinov and Kristjanson, 2014). Each session is audio recorded and later transcribed verbatim. The therapist then edits the manuscripts to create a 'legacy document' with a chronological storyline to share the person's personal story (Hack et al., 2010). The legacy document is then read with the patient which provides an opportunity for them to hear their recorded words, and clarify the content or correct any chronological errors.

Any amendments or errors are then corrected and often patients will request the inclusion of photographs to support their legacy document. A final hard copy of the legacy is then handed to the person which can be shared with family and friends to promote generativity and transcendence of an individual once they have died (Passik et al., 2004).

### 2.3.1 - Psychological benefits of dignity therapy

A number of the articles identified ( $n=11$ ) had investigated the use of dignity therapy with palliative care populations (Chochinov et al., 2005; Tait et al., 2011; Montross, Winters and Irwin, 2011; Hall et al., 2011; Houmann et al., 2014; Bentley et al., 2014; Aoun, Chochinov and Kristjanson, 2014; Martinez et al., 2017; Vukasnovic et al., 2016; Bentley et al., 2017; Julião et al., 2017). Early findings on the effects of dignity therapy were published by Chochinov et al. (2005) with a sample of one hundred terminally ill cancer patients recruited from Australia and Canada. Baseline measures were collected using a psychometric battery of scales to assess physical, psychological and existential issues which were re-administered after the dignity therapy intervention to assess therapeutic influence. Notably, 91% ( $n=91$ ) of the sample reported feeling 'satisfied' or 'highly satisfied' with dignity therapy, 68% ( $n=68$ ) reported the intervention to be 'helpful' or 'very helpful'. The latter of these findings was significantly correlated with perceptions of life seeming to possess increased meaning ( $r=0.566$ ,  $p<0.0001$ ); a heightened sense of purpose ( $r=0.547$ ,  $p<0.0001$ ); and an increased will to live ( $r=0.290$ ,  $p<0.004$ ). It was also noted that participants with the highest baseline measures of distress benefited the most from dignity therapy. Attrition was notable in the

study with a completion rate of 71% as a consequence of death ( $n=14$ ), or significant deterioration ( $n=15$ ).

A later study conducted by Chochinov et al. (2011) extended these findings through conducting a large scale randomised controlled trial with participants recruited from Australia, Canada and America who had a terminal cancer diagnosis. Baseline measures were collected using the; Palliative Performance Scale (PPS) (Anderson et al., 1996), Patient Dignity Inventory (PDI) (Chochinov et al., 2008), FACIT-Sp (Peterman et al., 2002) and HADS (Zigmond and Snaith, 1983). Participants were then randomised into one of three conditions; dignity therapy ( $n=108$ ), standard palliative care ( $n=111$ ), or client-centred care ( $n=107$ ). Dignity therapy was carried out during three to four visits by a trained dignity therapist over a period of 7-10 days. Post-intervention measures were later obtained by re-administration of the psychosocial questionnaires and scales used for baseline measurements, in addition to a dignity therapy satisfaction questionnaire. Participants in the dignity therapy group reported a plethora of benefits compared with the other two study groups. Notably, the dignity therapy group reported increased QoL ( $\chi^2=14.52$ ,  $p=0.001$ ), heightened sense of dignity ( $\chi^2=12.66$ ,  $p=0.002$ ), and additionally, perceived that it had changed how family members saw and appreciated them ( $\chi^2=33.81$ ,  $p<0.0001$ ). Critically, however, the participants recruited for the study were generally older, with an overall mean age of 65 years. Additionally, the sample was predominantly diagnosed with terminal malignancies with a prognosis of less than six months. As such, the findings may not be transferrable to younger patients with alternative terminal illnesses

which often result in longer periods of palliative care. Moreover, whilst the JBI appraisal indicated that the article was of high quality, there was a key limitation regarding the provision of the intervention for each participant group. Chiefly, the authors do not document the duration of time spent with either cohort of participants. It is therefore not possible to ascertain whether the findings are attributable to the intervention, or potentially, due to increased time with facilitators.

Additional benefits of dignity therapy for terminally ill patients have also been identified by Houmann et al. (2014). In this Danish study with 101 terminally-ill cancer patients, dignity therapy was reported by patients to be helpful, made life more meaningful and increased a sense of purpose. Furthermore, a follow-up assessment two-weeks after the dignity therapy intervention suggested that patients' sense of burden had decreased, whilst dignity had increased. Similarly, Vukasnovic et al. (2016) recruited 70 Australian palliative care patients and, based on post-intervention self-report measures with a sample of 56, the researchers identified dignity therapy to bolster meaning in life, a sense of value and was deemed a helpful intervention. Furthermore, carers and family members of the participants also reported dignity therapy to have reduced sadness and depressive symptoms in the patient. However, limitations to the research lie in the predominantly female sample ( $n=31$ ), with the majority having a malignant terminal illness ( $n=29$ ). As such, the generalisability of these findings and potential transferability of suggested positive dignity therapy outcomes may only be limited to this specific

demographic. Regardless of such limitations, this paper achieved a high indicator of quality based upon JBI appraisal.

## **2.4 - Alternative approaches to stimulate life review**

A number of studies have investigated alternative methods to promote and engage people approaching the end of life to reflect on life ( $n=8$ ). One such approach is a family based intervention whereby a legacy is co-created between the person with a terminal illness and family members (Allen et al., 2008; Allen 2009). Music has also been identified as a way to evoke memories and support life review interventions (Cadrin, 2006; Sato, 2011). Similarly, Redhouse (2011) outlined drama therapy as an approach for life review. Participants select a specific photograph and narrate the various thoughts, feelings and memories that are evoked. Senses can additionally be stimulated through provision of particular smells, tastes and sounds. In contrast, the use of digital resources has also been identified as an effective way for people with a terminal illness to reflect on life and create a legacy. Creating a public legacy through writing an online blog, allows people with a terminal illness to tailor the memories, pictures and experiences that they wish to share with others (Keim-Malpass, Adelstein and Kavalieratos, 2015). Alternatively, creating a legacy by recording videos has also been highlighted as a potential way to support interventions which encourage people approaching the end of life to reminisce (Kogan et al., 2017; RecordMeNow, 2017).

#### 2.4.1 - Psychological benefits of alternative approaches to stimulate life review

The use of music to stimulate reflection and reminiscence was identified in two articles (Cadrin, 2006; Sato, 2011). Listening to specifically chosen songs by patients receiving palliative care, can not only evoke memories to assist with life review, but also provide a sense of relaxation, lift mood and enhance cultural heritage (Sato, 2011). In a series of three case studies conducted by Cadrin (2006), one participant was a plwMND. Three songs were selected which the plwMND felt summarised distinct phases and achievements throughout her life. These songs were narrated by the participant and later compiled by the facilitator into a music legacy to be given to the plwMND's family. Alongside this, a journal was written containing memories and providing advice and guidance to her family. Upon completion, an evaluation was conducted with the plwMND who indicated a reaffirmation of purpose, increased self-worth, and sense of transcendence knowing her thoughts and beliefs had been captured in the legacy. However, such positive outcomes should be viewed in light of some study limitations affecting the transferability to other patients and plwMND. Crucially, the plwMND is described in the case study as having a strong spiritual faith which is known to impact positively on coping with the disease (O'Brien and Clark, 2015). It is therefore not possible to ascertain whether positive outcomes would be similarly gained with other plwMND. This concern was further strengthened during the JBI assessment of study quality. The author of the paper provides only brief clinical information regarding the participants involved in the study. This further contributes to the aforementioned issue of transferability.



An alternative approach to life review was investigated by Allen et al. (2008). This sought to assess the feasibility and efficacy of a family based intervention which aimed to increase the perception of meaning for terminally ill patients and family members. Forty-two palliative care patient and caregiver dyads were recruited from community healthcare agencies and hospitals in America, with 31 of these completing the follow-up assessments. Dyads were then randomly assigned to either an intervention group ( $n=17$ ), or control group ( $n=14$ ), and completed a selection of pre-post outcome measures.

Participants allocated to the intervention group were visited three-times weekly by a trained interventionist and were to identify a specific time or period from the terminally-ill patient's life that the legacy would be focused upon. The interventionist then provided a list of potential legacy projects which could be created. The most commonly selected legacies were photo-albums, scrapbooks and cook-books or recipes. Upon completion of the study, significant findings were identified for improvements in talkativeness between patients and caregivers ( $F(1, 27) = 6.21, p = 0.019, \eta^2 = 0.187$ ). Furthermore, whilst the intervention group reported increased talkativeness over time, the control group indicated a decline over time in the same domain. This finding was also reflected within caregiver self-reports of patient talkativeness. Consequently, 14 of the intervention group dyads (84%,  $n=31$ ) expressed that family communication had greatly improved after the legacy project. However, as noted whilst conducting the JBI assessment of quality, these are tentative findings with the transferability being questionable due to a predominantly African American sample recruited for both the intervention group (79%,  $n=11$ )

and control group (71%,  $n=12$ ). Moreover, an additional phase of data collection to investigate the perceived benefits of the intervention, may have enabled an assessment of intervention longevity. Regardless of this, the intervention was clearly well received with 90% ( $n=15/17$ ) reporting that they would continue working on the legacy upon study completion.

Secondary analysis was later conducted by Allen (2009) through exploring the interview narratives generated during baseline assessments in the previous study (Allen et al., 2008). It was identified that whilst some patients sought a written legacy documenting their complete life, it was important to recognise the time and efforts required to create this. Therefore, the legacy must be an achievable project without enforcing an overwhelming burden on those involved. It was also reported that disparities arose between patients requesting to create a written legacy, whereas partners emphasised the importance of preserving the patient's voice through creating a type of digital legacy with audio-recordings. Irrespective of the legacy format, dyads expressed a benefit from undertaking a meaningful project which endorsed communication, prompted difficult conversations, and, developed a legacy which could be passed on to children and future generations. Moreover, the project encouraged the dyads to spend quality time together in the final days of the patient's life.

In contrast, an alternative approach to creating a legacy is using technology to create a 'digital legacy'. It is argued that this umbrella term encompasses a plethora of digital information attached to a person's identity (Bassett, 2015). As such, a digital legacy may constitute internet browser history, emails, online social media profiles, and even online file and data storage. However, one

aspect of a person's digital legacy may also be a collection of digital memories. Similar to traditional memory boxes, digital formats of photographs, videos, messages, music or blogs can contribute to an individual's digital legacy through creating a type of 'digital memory box' (Bassett, 2015). This reinforces ideas postulated by Allen et al. (2008) through exemplifying the mutually beneficial characteristics of legacies in digital forms through suggestion that:

*'[...] since these biographies belong in digital memory boxes; they enable storytelling, on-going narratives, memorialization and "renegotiated" relationships with the dead in a digital afterlife.'* (p.4)

There are a variety of methods through which a person can create a digital memory box, and consequentially, a digital legacy. The approach to building the legacy is dependent upon their personal preferences, intended outcome and format. Due to the increase of smartphone and technological device functionality, people can independently compile a variety of digital memories with relative ease. Furthermore, it is possible to create new or spontaneous material with these devices, without the necessity of labour intensive preparation and involvement from a trained therapist.

Whilst some people may prefer to record material using a relatively organic approach with a sense of spontaneity in the content, others favour utilising specifically created digital legacy software and platforms. Online services such as DeadSocial<sup>®</sup> and SafeBeyond<sup>®</sup> enable users to create a digital legacy through uploading digital content to internet based platforms for a nominal fee. Similar to traditional legacies, these digital legacies are then transferred to a previously identified family member or friend upon the user's death. In

contrast, other downloadable programmes and software encourage users to create digital legacies in a specific format. One of these, developed in 2005, is called RecordMeNow<sup>®</sup> and currently free of charge. This enables users to record a video-based digital legacy in response to prompting questions to generate a digital legacy specifically to be bequeathed to a child or young person in the user's family. Video responses to the prompting questions are recorded using either a plug-in webcam and microphone, or alternatively, Apple smartphone or tablet. These questions are based on research conducted by RecordMeNow<sup>®</sup> between 2007 and 2012 with 100 parentally bereaved young people who identified common unanswered questions about their deceased parent and their life (RecordMeNow, 2017). These were later compiled into prompting questions to which users can video-record their response, modify the question, delete, or add their own. Upon completion, the videos can be stored online, or transferred to a tangible resource such as a DVD or USB stick to be bequeathed to a young person as a digital legacy.

An alternative approach is LifeChronicles<sup>®</sup> which incorporates elements of the previously described life review for the elderly and seriously ill (LifeChronicles<sup>®</sup>, 2017). The LifeChronicles<sup>®</sup> intervention was developed in 1998 after recognising a number of limitations with existing autobiographical approaches. Most notably, interventions such as therapeutic life review and dignity therapy require multiple sessions, often long in duration, conducted by a trained therapist (Kogan et al., 2017). Similar to these interventions, LifeChronicles<sup>®</sup> encourages people to reflect during a videotaped interview

regarding five key topics; life story, relationships, legacy/lasting messages, personal philosophy, and finally, health trajectory/medical experience (LifeChronicles®, 2017). The duration of the interview is approximately 90 minutes with raw footage then edited by the facilitator to create the final video-based digital legacy for the patient and their family.

Whilst there is currently little published research regarding LifeChronicles®, a secondary analysis of satisfaction surveys was conducted by Kogan et al. (2017) in an article which achieved a JBI high indicator of quality. In total, fifty-one participants completed an evaluation survey regarding their experience of the LifeChronicles® intervention. The majority of respondents ( $n=50$ ) rated the intervention as 'great' and 'would recommend LifeChronicles® to someone else'. Furthermore, participants commented upon a sense of empowerment and feeling '*emotionally, spiritually, and relationally very full and complete*' following the intervention (Kogan et al., 2017, p.2). While this is the first empirical investigation to a videotaped and modified version of life review, the authors suggest that the approach provides a feasible and well-received intervention to attend to the holistic needs of people with a serious illness. As such, Kogan et al. (2017) outline the need for additional research in this area to investigate the impact of the video-based legacy for surviving family members.

## **2.5 - Summary**

This chapter has presented a review of literature regarding a variety of interventions which encourage people with a terminal illness to reflect upon life and create a legacy. Due to there currently being a gap in the literature which specifically focuses upon plwMND creating a legacy, it was necessary to broaden the review to include alternative terminal illnesses. It has been highlighted that reflecting upon life and creating a legacy, may provide a number of psychological benefits for people approaching the EoL. Furthermore, existing literature also infers that creating video based digital legacies may provide additional and alternative benefits for people living with a terminal or serious illness.

Within the next chapter, a review of literature will be presented investigating the various ways in which bereaved young people continue bonds with the deceased. This review will follow the same literature search method adopted for the current review, as outlined at the beginning of this chapter (pages 12-15).

## Chapter 3 - Literature review two

“To live in hearts we leave behind is not to die.”

Thomas Campbell (1777-1824)

The previous chapter provided a review of the literature investigating a variety of interventions which encourage people with a terminal illness to reflect upon their life and create a legacy. Developing this further, the current chapter will provide background information and a review of literature investigating how bereaved young people continue bonds with deceased family members.

### 3.0 - Background

It is estimated that approximately 111 children become bereaved daily in the United Kingdom following the death of a parent (Child Bereavement UK, 2017). Until recent years, the dominant ideology regarding grief and bereavement stemmed from early theories provided by Freud (1957). This emphasised the need for people to engage in ‘*a very distinctive psychic task [...] namely to detach the memories and expectations of the deceased*’ (p.96).

As such, mourning was focused upon a process of relinquishing bonds with the deceased during a specific period following the death of a loved one (Gorer, 1967; Irwin, 2015). An inability to sever the relationship and bonds with the deceased was considered ‘*symptomatic of pathology*’ and prevent the ability to develop new relationships (Silverman, Klass and Nickman, 1996,

p.5). It was therefore necessary for bereaved people to '*leave the deceased behind*' in order to be resolute and come to terms with the death of a loved one (Walter, 1996, p.2).

This concept of successful bereavement requiring a level of detachment from the deceased, was similarly proposed by Bowlby (1979). However, in contrast to Freud (1957), Bowlby suggested grief to be a process of attempting to re-establish and maintain attachments with the deceased. This seeking of connection eventually terminates and the bereaved *detach* bonds from the deceased when they realise that the previous relationship will never be replicated (Marwit and Klass, 1995). Bowlby (1979) based this theory on his earlier work observing how children reacted when separated from their mothers. The observed children would initially protest before completely detaching themselves from their mothers after being separated. Bowlby therefore applied these observations to the process of death and grief and argued that all forms of mourning lead to detachment (Van Heerden, 2003). However, whilst Bowlby's initial theory on loss and grief supported Freudian ideas of detachment, he later acknowledged that many bereaved people maintain a '*continuing presence*' with the deceased, and that this bond can be '*a common feature of healthy mourning*' (Bowlby, 1980, p.100).

This theory of attachment and detachment in the light of loss and grief was later developed by Parkes and Weiss (1983). An emphasis was directed towards the psychosocial transitions required by the bereaved following the



death of a loved one (Madison, 2005). As such, the bereaved must engage with three grief related tasks in order to successfully negotiate bereavement; intellectual acceptance, emotional acceptance, and finally, construction of a new identity with the deceased no longer present.

An additional theory of loss and grief has also been outlined by Kübler-Ross (1969). This advocates grief to be centred upon five distinct stages which must be moved through sequentially; denial, anger, bargaining, depression, and lastly, acceptance (Kübler-Ross, 1969). This model originated from observations and interviews conducted with patients living with a terminal illness. It was later applied to not only those facing death, but also people who had experienced loss and bereavement. Unique to this theory, is the idea that each person will have an individual response to their loss, yet tend to follow a predictable format (Madison, 2005). However, this model has been criticised due to a lack of empirical evidence which fully demonstrates the binary nature and transition between each of the stages (Kastenbaum, 1998).

In contrast to these traditional ideologies which originated from clinical perspectives, later theories began to acknowledge the changeable nature of grief (Wimpenny and Costello, 2012), and influence of society and culture (Thompson, 2002). This prompted the development of the 'dual process model' by Stroebe and Schut (1999) who believed that the existing models of grief were inadequate in their explanations. As suggested in the name, this model infers two processes named '*loss orientation*' and '*restoration orientation*'. The former refers to the way bereaved people reflect and dwell

upon the significance and sadness associated with their loss. In contrast, restoration orientation refers to a process of looking forward and considering how life will be different for the bereaved, now that the person has died (Thompson, 2012). Unique to this more contemporary model, is the idea that bereaved people will 'oscillate' between both of these orientations whilst grieving (Wimpenny and Costello, 2012). As such, grief work is not based upon a series of stages and phases which must be sequentially negotiated over time, but instead, '*a waxing and waning, an ongoing flexibility over time*' (Stroebe and Schut, 1999, p.212). It is suggested that over time, the bereaved will gradually spend less time in loss orientation, and more in restoration orientation. However, throughout life, it is possible to temporarily oscillate back to loss orientation (often with fleeting thoughts or reminders of the deceased) before returning to restoration orientation (Thompson, 2012).

Similarly, the 'continuing bonds model' which was first proposed by Silverman, Klass and Nickman (1996), also suggests bereavement to be a process of adaption and change. As such, bereavement is not a linear process which can ever be fully resolved. It is instead argued that '*people are changed by the experience [of bereavement], they do not get over it, and part of the change is a transformed but continuing relationship with the deceased*' (Silverman, Klass and Nickman, 1996, p.19). Consequently, bereaved people do not engage in a process of disconnecting with the deceased but, instead, develop new and alternative bonds with them (Irwin, 2015). As suggested by Worden (1991), bereavement is less about an individual giving up their relationship with the deceased, but to '*find an appropriate place for the dead in their emotional lives*'

(p.16). With this in mind, a pivotal element of loss and bereavement is to construct a new and alternative identity of the deceased, thus enabling a continued presence within the lives of survivors (Madison, 2005).

This idea was developed further by Walter (1996) in his theory of a biographical model of grief. The model drew more upon the social context of death, dying and bereavement which highlighted the importance of talking to other survivors about the deceased in order to create a '*durable biography*' (Walter, 1996). He based this theory upon his own personal experience following the death of his father and a close friend. Within the paper, Walter describes a process of '*writing a last chapter*' in which he '*began to find a stable place*' for his deceased friend, in his own life, following her death (p.13). The '*last chapter*' therefore developed through talking to others about the deceased, discussing old memories, and learning about new or previously unknown information. Developing this durable biography allows the bereaved to learn about the person who has died. Additionally, however, the process enables the bereaved to develop a broader understanding of how the deceased has influenced, shaped and contributed to the life and identity of themselves (Walter, 1996). As such, developing a durable biography by '*writing*' this last chapter, is predominantly a social process requiring input or stories from other survivors who knew the deceased. Information may be obtained through public domains like obituaries or conversations during the funeral (Walter, 1996). Alternatively, biographical information may be acquired through resources that were once written or created by the deceased such as photographs, diaries or memory boxes.

This concept was further extended and developed by Fearnley (2015) who conducted interviews with bereaved children, surviving parents and professionals involved in palliative and bereavement care. She postulates that young carers of a family member with a terminal illness, will often create a '*penultimate chapter*', which precludes the '*last chapter*'. This penultimate chapter will be revised and adapted many times as the condition of the person living with a terminal illness gradually worsens. Consequently, the young person's knowledge of the family member will encompass a plethora of illness related biographical information. This understanding will then be synthesised with newly acquired information during the writing of the last chapter once the person has died (Fearnley, 2015). However, young people are often sheltered from critical information during the person's illness, thus restricting the accuracy and breadth of their penultimate chapter. Successful synthesis of both chapters will therefore promote the development of a stable, secure and durable biography. This will provide a comprehensive understanding of the deceased's unique identity, and outline how they have influenced the lives of the bereaved which promotes a sense of a continued bond.

It was therefore proposed that a digital legacy created by a plwMND, may provide an alternative way for bereaved young people to develop their durable biography. With this in mind, a narrative review was conducted to answer the question; *How do bereaved young people continue bonds with the deceased?*

### **3.1 - Search method**

In accordance with the literature search method outlined in the previous chapter (pages 12-15), the following key words ["continued bond" OR "continuing bonds" OR "last chapter" OR "penultimate chapter" OR "relationship" OR "construct\*"] AND ["child\*" OR "teen\*" OR "adolescent\*"] were searched for within article titles.

#### **3.1.1 - Inclusion/exclusion criteria**

Dates for inclusion of articles were limited from 1996 to 2017 in accordance with the concept of continuing bonds being first published in 1996 by Silverman, Klass and Nickman. Unpublished dissertations, theses, or non-peer-reviewed articles were excluded. Language limiters were applied for articles published in English. All study designs and both quantitative and qualitative methodologies were included. Finally, articles which had not focused on bereaved young people were omitted. The majority of these articles were focused upon parents who were bereaved due to the death of a child.

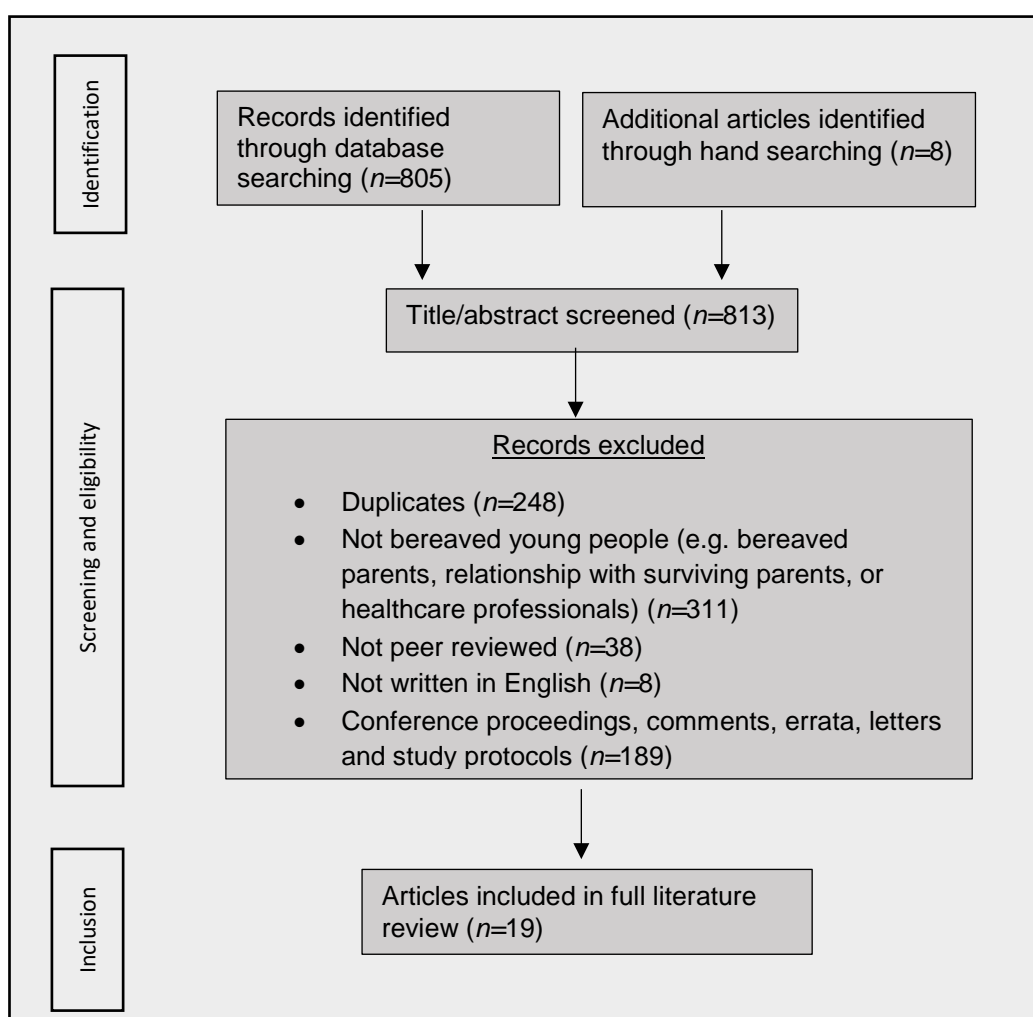
#### **3.1.2 - Search results**

A summary of the search results is provided below in Figure 3. In total, 805 hits were returned with a further eight papers identified through hand searching. The majority were ruled out due to duplication (n=248), or, incorrect focus upon parental loss of a child, bereaved young people's relationship with surviving parents, or healthcare professionals (n=311). Following scrutiny of

the remaining article titles and abstracts, 19 met the inclusion criteria and were reviewed in accordance with the process described earlier in this thesis (pages 12-15). A summary of all included papers and respective indicator of quality scores created from the JBI tools is provided for clarity (see appendix 1).

Articles were then synthesised into three over-arching themes of; *unintended connections*, *intended connections*, and, *internalised connections*. Each of these themes will be discussed in turn.

Figure 3- A summary of search results



### **3.2 - Unintended connections**

The experience of bereaved young people having unintended connections with the deceased was outlined in ten articles (Normand, Silverman and Nickman, 1996; Field, Gao and Paderna, 2005; Packman et al., 2006; Brewer and Sparkes, 2011; Foster et al., 2011; Wood et al., 2012; Root and Exline, 2014; Hansen et al., 2015; Irwin, 2015; Simpkins and Myers-Coffman, 2017). This is the idea that bereaved young people often feel a sense of connection with the deceased, through natural and spontaneous occurrences. One of the earliest articles which highlighted this as a potential way in which bereaved young people continue bonds with the deceased, was a literature review conducted by Field, Gao and Paderna (2005). The authors highlight that often, bereaved young people have fleeting reminders and hallucinations of the deceased. These experiences are often naturally occurring and not explicitly sought by the young person. However, experiencing such vivid reminders of the deceased is suggested to provide an unprovoked reminder of their absence in the young person's life.

Similar findings were also described in a later literature review which investigated continuation of bonds in young people following sibling bereavement (Packman et al., 2006). It was highlighted that bereaved young people often experience a sense of presence from the deceased, feeling as if the person is around them and watching over them. This was perceived to be a positive experience through providing a sense of connection with the

deceased, particularly during periods of hardship. In contrast, a later literature review described this experience and feeling of being contacted by the deceased to be a potential source of distress for some bereaved young people (Root and Exline, 2014). The authors outline that having spontaneous and unplanned thoughts of the deceased, may provide the young person with a sense of the deceased initiating contact with them. As such, the young person has little control over their own thoughts, meaning the deceased can influence their cognitions from the grave. This additionally raises the potentiality of confusion whereby the bereaved have become accepting of the physical absence of a loved one, yet, they are still somehow initiating contact and influencing the young person's thoughts.

Whilst informative, all of these literature reviews possess methodological limitations due to a lack of transparency regarding search strategies employed and eligibility criteria for articles (Field, Gao and Paderna, 2005; Packman et al., 2006; Root and Exline, 2014). However, a number of additional empirical studies have similarly reinforced the concept of unintended connections occurring in bereaved young people (Norman, Silverman and Nickman, 1996; Foster et al., 2011; Hansen et al., 2016; Simpkins and Myers-Coffman, 2017).

One of these studies was conducted with nine parentally bereaved adolescents who were recruited from a hospice in America (Hansen et al., 2016). Open ended interviews were conducted to explore how they perceived their relationship with their parent to have changed following the death. The



young people commonly described 'encounters' or unexpected interactions with their dead parent. These were commonly sudden 'appearances', feeling like they were being watched, or, having internal conversations with their deceased parent. Similar findings were also outlined in a larger scale study with 24 bereaved children aged six to 17 years old, also conducted in America (Normand, Silverman and Nickman, 1996). The bereaved young people commented upon being able to 'hear' the deceased when they communicated with them. Such experiences tended to occur during the earlier stages of loss, and, to be more prevalent for the younger participants.

In contrast, a later study identified young age not to be a contributing factor in bereaved young people experiencing unintended or spontaneous encounters with the deceased. In a novel study of Facebook profiles from 12 deceased people, 1270 posts that were written by bereaved friends to the deceased were analysed (Irwin, 2015). As such, the majority were aged between 18 to 25 years old, and commonly wrote to the deceased to describe experiences, messages and visitations which were interpreted to be from the deceased. This suggests that experiencing spontaneous and unintended connections with the deceased, may not be distinct to only younger children. Critically, however, limitations for this study lie in the public nature of mourning on Facebook. Irwin (2015) describes that the posts tended to be written as if it was a private and personal message to the deceased. Yet, posts on memorial pages are published with an awareness that other survivors will read the content. It is therefore unclear whether survivors are attempting to

communicate with the deceased, or, drawing upon Walter's concept of the last chapter, attempting to gain information and stories from other survivors (Walter, 1996). Regardless of this, it is clear from a number of articles that bereaved young people tend to hold beliefs that the deceased still exist in some form and remain able to see and hear the young person (Silverman et al., 2002; Foster et al., 2011; Wood et al., 2012; Pennington, 2013).

Also prominent within the literature, was the concept of unintentional stimulation of senses to re-establish a connection with the deceased (Simpkins and Myers-Coffman, 2017). One of these studies was conducted in the United Kingdom through conducting semi-structured interviews with a sample of 13 parentally bereaved young people (Brewer and Sparkes, 2011). Based upon the findings from the study, the authors suggest that *'sight, sound, touch, taste and smell, individually or collectively, can act as a bridge in the continuity of relationships'* (p.289). Such findings were similarly reinforced in a small scale American study with three bereaved young people (Simpkins and Myers-Coffman, 2017). It was specifically identified that memories were commonly evoked through unintentional exposure to special songs that reminded the bereaved young person of the deceased. Interestingly, both of these studies highlight that a connection with the deceased can be re-established through unintended and spontaneous exposure to a stimulus. Yet, of further interest, is that bereaved young people may purposefully seek ways to stimulate their senses in order to control their continued bond with the deceased.

### 3.3 - Intended connections

A number of the articles ( $n=10$ ) highlighted that bereaved young people will often purposefully seek the use of stimuli in order to create an intentional connection with the deceased (Normand, Silverman and Nickman, 1996; Nickman, Silverman and Normand, 1998; Christ, Siegel and Christ, 2002; Saldinger et al., 2004; DeVreis and Rutherford, 2004; Packman et al., 2006; Brewer and Sparkes, 2011; Foster et al., 2011; Wood et al., 2012; Pennington, 2013). One of the earliest articles was based upon data collected in America using semi-structured interviews with 24 parentally bereaved young people (Normand, Silverman and Nickman, 1996). A common method for young people to maintain a connection with the deceased, was through maintaining and preserving memories of their parent. Often this would require stimulation through use of objects and mementos that were once owned by their parent. Objects therefore became a link with memories of their parent providing what the authors describe to be a *'bridge between the world with and world without one parent'* (p.91). A later article by the same authors identified objects such as photographs, jewellery and clothing to be commonly used by the bereaved young people to 'bridge' the gap (Nickman, Silverman and Norman, 1998). However, it was also noted that a conflicting coping mechanism for some surviving parents is to dispose of, or hide, objects that remind them of the deceased. Whilst the use of objects to reconnect with the deceased gradually reduces over time, the premature disposal of mementos may create additional challenges for a bereaved young person. Critically, however, a clear limitation of both studies is that the findings are now somewhat dated.

Regardless, later empirical research has also evidenced the importance of objects for bereaved young people. In a study with 39 siblings, bereaved young people, 44% ( $n=17$ ), discussed playing with toys and personal belongings once owned by their deceased sibling to feel connected with them (Foster et al., 2011). Similarly, the bereaved young people also described the purposeful use of scrapbooks and photographs in order to '*go back to the memory*' associated with the stimuli (p.429). The use of photographs, videos and audio recordings, have additionally been described to bolster a sense of connection with the deceased through providing a way to recognise physical and audio similarities between the young person and deceased (Brewer and Sparkes, 2011). Within this UK based retrospective study with 13 parentally bereaved young people, it was reported that visual and audio representations were the preferred method for connecting with the deceased. In accordance with the previously mentioned 'bridge' bereaved young people require with the deceased, Brewer and Sparkes (2011) outline that '*sight, sound, touch, taste and smell, individually or collectively, can act as a bridge in the continuity of relationships between the living and the dead for parentally bereaved young people*' (p.289).

Consequently, many hospices now encourage patients to create resources such as memory boxes for young people in their family to use in the future. Similarly, bereaved young people may also create a memory box which contains the various objects and photographs which elicit happy memories and provide a connection with the deceased. Further described in a qualitative UK based study with ten bereaved young people, memory boxes provide

young people with an important sense of control regarding where and when memories of the deceased are evoked (Wood et al., 2012). It can therefore be argued that the process of creating a memory box can also support the development and refinement of the deceased's last chapter (Walter, 1996).

However, additional research with 58 parentally bereaved young people, suggests that the most treasured objects and mementos were those that were specifically created by a parent before death. Saldinger et al. (2004) conducted semi-structured interviews and identified mementos such as videos and letters to be commonly used by the bereaved young people to reconnect with the deceased. These were often revisited throughout the young person's life in accordance to developmental stages whereby understanding of the content would be gradually refined (Biank and Werner-Lin, 2011). Furthermore, interviews with the surviving parents outlined that many of the dying parents gained a sense of enhanced parenthood, and the ability to '*parent beyond the grave*' through creating the mementos (Biank and Werner-Lin, 2011, p.932). However, such findings are tentative due to the qualitative data being provided through proxy accounts from the surviving parents regarding the experiences of the deceased parent prior to death.

An alternative way in which bereaved young people continue bonds with the deceased, is through a purposeful use of internet based resources (DeVries and Rutherford, 2004; Pennington, 2013; Irwin, 2015). The earliest of these articles investigated the characterisation of an online memorial site (DeVries and Rutherford, 2004). A sample of 5% (n=244) of memorial posts made to the site were thematically analysed to ascertain that the majority were written

as letters from bereaved young people (n=111). As such, writing online letters to the deceased was suggested as an important way in which young people continue bonds with the deceased. This has similarly been identified in later studies which focused on the use of Facebook (Pennington, 2013; Irwin, 2015; Hansen et al., 2016). An American study collected qualitative data with 43 bereaved young people aged between 18 to 24 years old (Pennington, 2013). Each of the young people were a mutual friend on Facebook with a deceased peer. Interviews were conducted to identify that Facebook provided a platform in which bereaved young people continue a connection with the deceased through writing posts on their wall. Additionally, mutual friends could read the posts written by other bereaved peers to gain insight to new stories of the deceased which supported the development and refinement of their last chapter (Walter, 1996).

Similarly, the importance of sharing and hearing new stories about the deceased has additionally been reported through more traditional means. A literature review conducted by Christ, Siegel and Christ (2002) outlined it to be essential that bereaved young people have memories evoked by other surviving adults. Often such memories are evoked immediately after the death, or during the funeral, when stories are frequently shared. However, this sharing of information about the deceased gradually decreases over time meaning bereaved young people may not have special memories evoked. Whilst limitations of this literature review lie in the lack of detail that is published regarding the identification and selection of articles, similar findings have also been reported in later empirical research (Pearce, 2008; Foster et al., 2011; Fearnley, 2015).

### **3.4 - Internalised connections**

Reported within a number of articles ( $n=10$ ), bereaved young people maintain a connection with the deceased through internalising aspects of the deceased's values, beliefs, personality and identity (Normand, Silverman and Nickman, 1996; Nickman, Silverman and Normand, 1998; Christ, Sigel and Christ, 2002; Silverman et al., 2002; Field, Gao and Paderna, 2005; Packman et al., 2006; Pearce, 2008; Biank and Werner-Lin, 2011; Root and Exline, 2014; Hansen et al., 2016). This is arguably a later stage of bereavement for young people, whereby the use of objects and stimuli gradually diminishes over time as the permanence of death is internalised (Field, Gao and Padema, 2005). Over time, bereaved young people achieve a state of 'reconstitution' through adjusting their perception and understanding of their new relationship with the deceased (Christ, Siegel and Christ, 2002). The young person therefore develops new meaning to the relationship and finds alternative ways to connect with the deceased (Packman et al., 2006).

This concept has been reinforced by a qualitative study conducted with 23 bereaved young people and their families (Nickman, Silverman and Normand, 1998). Connection was seemingly maintained through the bereaved young people developing a new and alternative representation of the deceased. The authors suggest that this internal image develops from a preserved set of memories and knowledge regarding the parent who had died. Once this preservation has taken place, there is less of a need for the young person to use external stimuli to create a sense of connection with the person who has

died (Normand, Silverman and Packman, 1996). Instead, the young person has a stable representation of the person which they can draw upon when seeking to reconnect and remember their parent. It is therefore argued that this representation of the deceased becomes '*an important role model [and a] valued part of the bereaved's autobiography*' (Field, Gao and Paderna, 2005, p.284). This inner representation may also change and evolve over time as new information is obtained regarding the person who has died (Root and Exline, 2014). As such, bereaved young people will adjust schemas to accommodate new information regarding the person who has died (Field, Gao and Paderna, 2005).

Practical examples of internalising the memory and identity of the deceased has been noted in a number of articles (Silverman et al., 2002; Pearce, 2008; Hansen et al., 2016). One auto-ethnographic study conducted by Pearce (2008), described how a bond with her deceased mother was maintained through adopting aspects of her mother's identity within herself. The author additionally interviewed her sister and noted that memories of their mother were internally relocated following her death. Recollections were selected and drawn upon throughout bereavement to suit mood and situation. Such memories were described to '*diffuse and weave into all action, choices, and built [their] character*' (p.143). As such, the internalised representation of their dead mother influences and shapes their daily life, and become especially



important during milestone events. Clearly, a key limitation of this study is the small and somewhat subjective nature of an auto-ethnographic study, thus questioning the transferability of findings. However, similar findings were noted by Hansen et al. (2016) in their qualitative study with nine bereaved adolescents. The participants described how their dead parent became an 'inner guide', shaping their thoughts and behaviour according to how they felt their parent would have wanted them to be. Often this would occur through mentally playing back words or sayings associated with the deceased. This was described to reinforce a sense of connection with their parent through providing a sense of enduring contact.

In contrast, a larger scale study conducted by Silverman et al. (2002), outlined a series of potential challenges and difficulties when bereaved young people develop a negative internal representation. In total, 120 bereaved young people between the ages of 6 and 17 years old were recruited to take part in a semi-structured interview. It was identified that 'negative legacies' were often described by the bereaved young people. One such legacy adopted by the participants, was a fear or sense that they will also develop the same condition or disease which their parent had. The young people also described feeling as though they must *'fill the space their parent left'* (p.340) by adopting a parental role in the family home and caring for younger siblings. Additionally, the young people developed an awareness of some qualities and characteristics which were not desirable and hence, were rejected. Consequently, the internal

representation constructed by young people, may endorse a sense of negative connection with the deceased. As such, Silverman et al. (2002) outline the importance of young people becoming aware that their parent was an individual person in their own right. This promotes a sense of 'healthy bonds' whereby the young person can distinguish between both the positive and negative representations. They are then able to prioritise the assimilation of positive traits to their internal representation of their parent.

A limitation of this study lies in the sample of adolescents being classified as 'high risk' within the Child Behavior Check List (CBCL9) (Achenbach and Edelbrock, 1983). It is therefore unclear whether bereaved young people who are not deemed at risk, would similarly develop negative representations of the deceased. Regardless of this, application of findings from the study emphasise that the connection a young person experiences with the deceased, can be negatively influenced. It is therefore important that positive memories and stories of the person are prioritised to the young person, thus promoting the development of a positive internal representation of the deceased.

This is of pertinence for young people who are bereaved due to conditions such as MND. It can be argued that the internal representation developed by young people, will be shaped by the most recent memories of the person. Consequently, a negative image may be developed due to the physical

degeneration caused by the disease. Therefore, interventions which promote the development of positive internal representations, may be of benefit for bereaved young people. However, to date, there is a dearth in the literature which explores ways in which bereaved young people can be supported in developing positive internal representations to endorse healthy connections with the deceased.

### **3.5 - Summary**

This chapter has presented background information followed by a review of literature regarding ways in which bereaved young people continue bonds with deceased family members. It has been outlined that connections can sometimes be unintended and occur spontaneously. Bereaved young people also gain a sense of connection with deceased family members using methods of stimulation. Lastly, bereaved young people develop internalised representations of the deceased which ensure gradually evolve over time.

The next chapter will detail the methodology adopted for this study. This will discuss the theoretical and philosophical underpinnings which have been pursued for the study. Following this, the chosen methodological approach for the study will be presented: Interpretative Phenomenological Analysis (IPA).

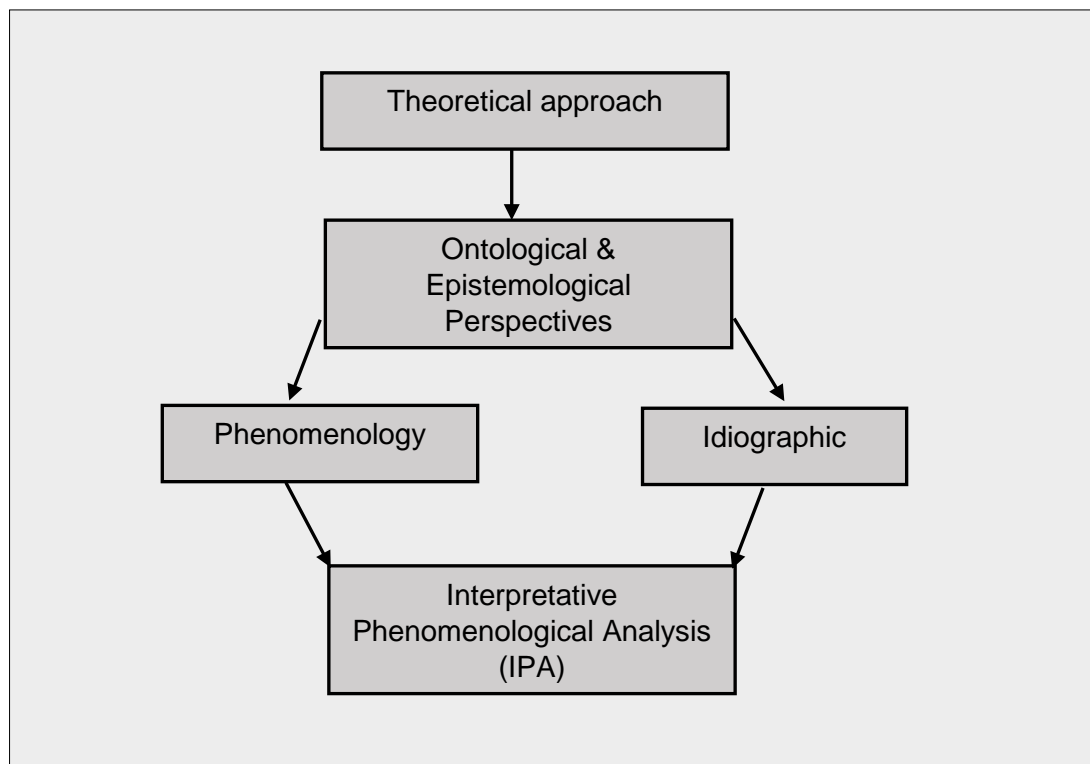
## Chapter 4 – Methodology

I believe in treating children as rational creatures with whom it is possible to discuss even the most serious matters. This makes a very profound impression on them, it strengthens their character and above all it avoids leaving their development at the mercy of random environmental pressures and casual, impersonal encounters. It really is very strange how grown-ups forget they were children themselves, and make no use of their own experiences.

Antonio Gramsci (1891-1937).

This chapter will present the theoretical stance that I have pursued for the research, and the philosophical concepts which underpin the study. I will first describe and explore the theoretical approaches for carrying out empirical research. I will then delineate two key philosophies which underpin the methodology which have shaped the development of this study. As such, existential phenomenology and the concept of idiographic approaches to research will provide the basis of this methodology section. As summarised below in Figure 4, I will finally introduce and explain the methodology that was adopted for this study- Interpretative Phenomenological Analysis (IPA).

*Figure 4- An overview of the theoretical and philosophical underpinnings for the study*



#### **4.1 - Theoretical approach**

There are two theoretical paradigms for carrying out empirical research, the deductive approach, and the inductive approach. A deductive approach for researchers involves hypothesis testing where theories or beliefs are either refuted or confirmed (Gray, 2014). This definition assumes that an explanation for the research phenomenon has already been suggested and the subsequent research will empirically test the underlying belief through predefined measures and experimentation. As such, a specific theory will guide the research (Bryman, 2008).

In contrast, an inductive approach to research sets out with no preconceived criteria to measure. Instead, observations and ideas regarding the phenomenon are generated to initiate the direction which the research will take. Thus, conclusions, theories and relationships regarding the research phenomenon are derived from the process of data analysis (Gray, 2014). Further, it is suggested by Cresswell (2013), that researchers *“build their patterns, categories, and themes from the “bottom up,” by organising their data inductively into increasingly more abstract units of information”* (p.45).

With this in mind, a deductive approach requires a set of predefined principles or criteria which can be observed or tested by the researcher. This is defined as a *quantitative* approach to research which endorses a focus upon the use of numerical or statistical methods to measure and test the preconceived hypothesis (Bryman, 2008). However, an inductive approach to research, such as my study, demands a recognition of human experience being broad and reflective. Subsequently, it is not possible to quantify experiences into binary categories to test and measure with numerical methods (Coolican, 2009). An approach which encourages participants to openly express their perception and experience of their lived-in world is therefore required in this study.

In contrast, a *qualitative* approach allows individuals to express themselves through use of their own language (Silverman, 2013). Accordingly, the focus of qualitative research is directed towards *how* an individual has made sense

of the research phenomenon and, chiefly, how they have attributed meaning and made sense of his/her experience through providing rich, or thick, descriptions (Smith, 2009; Smith, Flowers and Larkin, 2009).

The adoption of a purely quantitative approach for this study was therefore deemed inappropriate due to the focus being upon the experiential context of creating or using a digital legacy. My decision to adopt a qualitative methodology is further strengthened by it being commonly used in palliative care research. Qualitative approaches to research offer flexibility for exploration of sensitive issues, such as the ones investigated in this study, and, to investigate the experiences of terminally ill people (Scottish Partnership for Palliative Care, 2011). It has also been suggested that people who are receiving palliative care, and their carers, are more likely to report their participation in qualitative research to be positive and to have a beneficial impact on their well-being (Gysels, Shipman and Higginson, 2008). Qualitative research methodologies have also been identified as a successful approach for exploring the experiences of plwMND and their carers (Hanley, 2012; Aoun et al., 2011; Whitehead et al., 2011).

## **4.2 - Ontological and epistemological perspective**

Ontology is a philosophical term which relates to the assumptions that we make regarding our existence and being within the world, in addition to how we make sense of our reality (Breakwell, Smith and Wright, 2012). In the

1930s through to the 1960s, positivism was the dominant perspective adopted for social science research which argues that the social world occurs externally to a researcher (Gray, 2014). This suggests that reality can be rigorously investigated and measured through adoption of scientific and quantitative approaches to research (Cresswell, 2013). Consequently, a fundamental principle of positivism is the assertion *“that the only meaningful phenomena that can be studied scientifically are those that can be directly observed and measured quantitatively”* (Coolican, 2009, p.49).

Yet a strong criticism of this previously dominating ontological approach, is that not all ‘knowledge’ can be observed and/or measured quantitatively in order to test or generate scientific theories (Gray, 2014). Consequently, a juxtaposition arose between positivist approaches being utilised for social world research due to the overwhelming emphasis on the quantitative (Bryman, 2008).

A contrasting ontological perspective to positivism is that of social constructivism (Cresswell, 2013). This perspective suggests that truth, meaning and knowledge do not exist in the world we live in and cannot be observed through scientific measures. Instead, a social constructivist approach suggests that *“meaning is constructed not discovered, so subjects construct their own meaning in different ways, even in relation to the same phenomenon”* (Gray, 2014, p.20).



Constructivism promotes the concept of individuals possessing varied and multiple understandings of the world that they live in (Cresswell, 2013). Consequently, these varied understandings require a qualitative approach from researchers, thus encouraging the complexities of an individual's experience to be discussed in detail (ibid). This highlights the importance of an individual's use of language to 'construct' their knowledge regarding the research phenomenon (Willig, 2013). Consequently, their unique use of words, phrases, metaphors and clichés, will construct and transfer their personal experience of the research phenomenon onto the researcher (Breakwell, Smith and Wright, 2012). Also emphasised in the social constructivist ontology, is that each person will develop subjective meanings of an experience based upon social interactions with other people, in addition to utilising their past cultural and historical experiences (Cresswell, 2013).

This concept links heavily to the philosophical paradigm of epistemology, that is: *"knowledge of the world, and how it is acquired and constructed"* (Coolican, 2009, p.558). Whilst the ontology of social constructivism emphasises that an individual's experience, understanding and knowledge of the world is 'constructed' through interactions with the world and other people, the epistemological positioning questions *how* this construction becomes knowledge.

As previously discussed, a positivist approach tends to acquire knowledge predominantly through quantitative measures (Gray, 2014). Yet, criticism of this approach has been directed towards the epistemological perspective that human experience cannot always be decomposed into quantitative categories

measurable through scientific observation alone. Hence, the epistemological question is, then, 'how do we measure human experience to ascertain knowledge'?

In contrast to the positivist stance, is that of interpretivism. This concept is eminent in the aforementioned ontological concept of constructivism. Interpretivism advocates the generation of knowledge through gaining the unique and subjective meanings that individuals attribute to the research phenomenon (Cresswell, 2013). Consequently, social researchers endorse this epistemological stance through suggestion that qualitative research is “*a science which attempts the interpretative understanding of social action in order to arrive at a causal explanation of its course and effects*” (Weber, 1947, p.88).

Researchers must therefore adopt the attitude that an individual's construction of an event/experience, requires interpretation from the researcher themselves. Consequently, a researcher is aware that his/her own past experiences and knowledge will assist their interpretation of an individual's experience. Thus, a researcher will interpret and make sense of the meanings that have been attributed to the research phenomenon by the participant (Cresswell, 2013).

The poignancy of this ontological and epistemological underpinning within this study is that the experiences of being affected by MND and creating/using a

digital legacy will be highly unique for each participant. In turn, my personal experience of MND and use of a digital legacy further supports my interpretation of the experiences that individuals convey during the period of data collection.

### **4.3 - Phenomenology**

The philosophical approach of phenomenology is the 'study' of 'that what appears' (Smith, Flowers and Larkin, 2009, p.13). This is achieved by investigating a person's lived experience rather than their interpretation, or abstract views, of a particular experience (Finlay, 2009). The phenomenological movement began in the early 20<sup>th</sup> century with Edmund Husserl (1889;1927) who believed in the importance of examining how we perceive and make sense of our experiences (Smith, Flowers and Larkin, 2009). Husserl called this *transcendental phenomenology* and involves a process of careful examination and interpretation in order to make sense of a given phenomenon. Husserl theorised it was possible to strip down and isolate the essential characteristics that make the experience unique to existing knowledge regarding the phenomenon itself. Transcendental phenomenology has gained its name as it *transcends* and reduces a given phenomenon or experience to its core essences (Van Manen, 2014).

Husserl suggested that the way in which we experience the world is through a system of interrelated meanings- our 'life world' and this is the main focus of

phenomenology (Husserl, 1970). This is the way in which we perceive the objects and the world around us. Through this process we consciously attribute meaning and make sense of new phenomenon by relating it to existing knowledge. Although our lived-world occurs consciously, it is considered pre-reflective as we make sense of new experiences and interactions before we have a chance to explicitly think about them (Finlay, 2016). This means that our life-world is always consciously shaped by something, or someone, that we are interacting with. Phenomenologists are therefore attempting to decompose and highlight the interaction between a person's life world, their individual understandings, and what makes this specific interaction unique. Yet, Husserl believed that our life-world often overpowers and distorts our true understanding of an interaction by inappropriately applying existing knowledge that may be incompatible with the new experience or interaction (Smith, Flowers and Larkin, 2009).

Husserl also advocated the need to bracket, or 'epoché' (meaning 'to pocket' or 'suspend') our existing knowledge of the experience in order to adopt this transcendental phenomenological attitude. In setting aside our existing assumptions, we create a window of opportunity to view the experience in a different light and identify its core essence (Allen-Collinson and Pavey, 2014). This means that we openly seek to identify how things are experienced, instead of how they are perceived, when based upon and utilising our existing knowledge.

Husserl then suggested that once we have identified the features of a phenomenon which make the interaction unique, we begin a process of 'imaginative variation'. It is at this stage that we make a rigorous description of the experience and its specific characteristics such as the physical (colour, shape, texture), the experiential (our conscious thoughts and feelings) and the attributes necessary for this specific experience (time, space, relationship). During this phase, we also begin to gradually reapply our natural attitude to imagine new examples of when this experience may be required again and the limits to its appropriateness.

There are two key criticisms frequently associated with Husserl's transcendental phenomenology. Husserl attempted to describe phenomenology from a psychological point of view yet, being a philosopher, much of his writing presents a much more conceptual notion of phenomenology. Husserl rarely provides concrete examples or procedures to transcend experiences and instead, adopts a more philosophical and theoretical approach to a psychological issue of how we understand and comprehend experiences (Smith, Flowers and Larkin, 2009). Second to this, Husserl's phenomenology is based on his personal understanding of how he, himself, made sense of experiences. This brings into question whether it is possible to apply his assumptions as a generic theory to the overall population, when it is solely based on his own process of understanding new experiences (ibid).

Consequently, Husserl's phenomenological theory was later developed by Martin Heidegger in his major work called 'Being and Time' (1962). Whilst Heidegger remained phenomenological in his focus through attempting to understand how people make sense of their experiences, a significant contrast in ontological perspectives emerged between the philosophers (Van Manen, 2014). Accordingly, an alternative strand of phenomenology was developed by Heidegger and coined *existential phenomenology*.

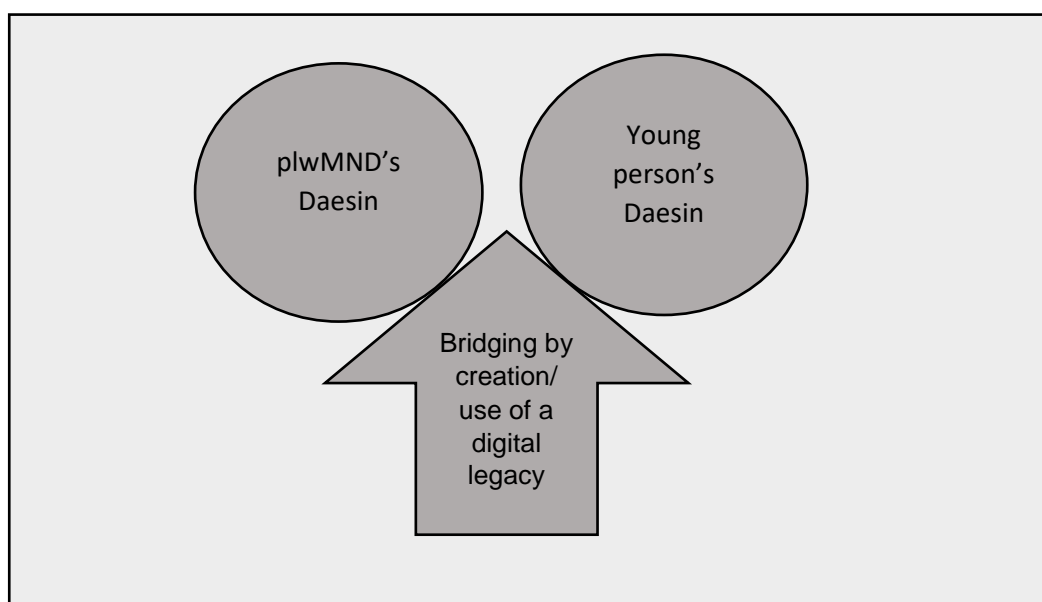
Crucially, Heidegger contested transcendental theories of being able to bracket knowledge and truly suspend existing assumptions. Instead, Heidegger suggested that we are inseparable from the world in which we live and therefore are unable to 'epoché' ourselves (Langridge, 2007). Therefore, in contrast to transcendental phenomenology, existentialists attempt to identify the *meaning* attributed to a given phenomenon, rather than attempting to identify the persons' *knowledge* of the phenomenon (Van Manen, 2014). As such, the ontological perspective adopted by Heidegger for existential phenomenology, is focussed upon his concept of 'Dasein' (meaning 'there-being'), and is applicable to anything that exists, as a being, in our world. Heidegger suggests that each of us are 'thrown' into a pre-existing world of objects, relationships, cultures and beliefs which we cannot detach from (Smith, Flowers and Larkin, 2009). As such, the way in which we exist, can only ever be interpreted by acknowledging the various influences from our individual environments, and the subsequent worlds into which we have been 'thrown'. Heidegger proposed that experiences must be interpreted according

to our individual world of objects, relationships, languages and history which we have been 'thrown' into and cannot be reduced to their core essences (Langridge, 2007). Heidegger therefore suggests that we possess a 'unity of being' or 'Mitsein' ('with-world'), in which we all have a shared overlap of how it is to exist in our world.

As such, the worlds and environments into which we have been 'thrown' are highly varied meaning we possess different attitudes, perspectives and beliefs of what it means 'to be' ('Daesin'). This perspective exemplifies the variation in how we, as people, will interpret new experiences, interactions with people, or, specific phenomenon differently due to each being 'thrown' into these unique existences and each possessing individual Daesin. Accordingly, the world that I have been 'thrown' into, and the existing knowledge I have of MND, creates a 'Mitsein' or shared understanding with participants of what it is like 'to be' affected by the disease. As advocated by Taylor (2014), this approach encourages an uncovering of shared meanings, rather than intending to draw comparisons between participants' experiences, and additionally the researcher's. Furthermore, my research investigates how a young person creates a new understanding of Daesin when the world that they are 'thrown' into changes, due to a family member living/dying with MND. As the disease causes physical deterioration, a young person's understanding of what it means 'to be' in his/her world will require adaption, alongside the deterioration of the plwMND. The creation of a digital legacy provides a concrete example of Mitsein with the stories and messages that have been recorded, explicitly

outlining the person's life, beliefs and values. In essence, a digital legacy provides a readily accessible 'Mitsein-bridge' between the plwMND and the young person (see Figure 5). In time, a young person may be able to develop their own unique Daesin by interacting with a digital legacy, which has been consciously recorded by the plwMND to accurately capture their own Daesin.

*Figure 5- A visual representation of a 'Mitsein-bridge' through use of a digital legacy.*



Heidegger (1962) further extended his concept of existential phenomenology through recognition of the words and language used by people. This hermeneutic approach emphasised language to possess a dual quality. As such, meaning is conveyed through having an explicit visible, or surface, meaning in addition to a concealed or hidden meaning. Furthermore, we may share a common understanding of particular words, and appropriateness of language, but we can never fully ascertain that the meaning we have attached



to a particular word, or use of language, is the same as another person's, due to our individual interpretation. As such, our language is individualised and interpreted according to our Daesin.

Heidegger suggested that a reader or analyst of text, can never objectively interpret the underlying meaning as intended by an author due to our individual perception of what it is 'to be' in the world (Daesin). He believed that an individual's explanation of an event or experience will always be interpreted by a researcher based upon their pre-existing knowledge and assumptions (Wilding and Whiteford, 2005).

*"[...] whenever something is interpreted as something, the interpretation will be founded essentially upon the ... fore-conception. An interpretation is never a pre-suppositionless apprehending of something presented to us"*

*(Heidegger, 1962, p.191-192)*

Heidegger explains this interpretative process further with the concept of a 'hermeneutic circle'. This suggests that a reader of a text already possesses a fore-understanding of the subject or experience being discussed. Consequently, there must be an openness to learn more and extend their existing knowledge regarding the subject matter. The reader will then reach a 'barrier' to which their existing knowledge will be challenged and require alteration to fully comprehend the intention and meaning behind the text. Due to this barrier, the reader will need to reassess their existing knowledge and create interpretative revisions of current understanding to make sense and overcome this barrier.

*“The hermeneutic circle thus moves between question and answer; between the implicit pre-understandings and explicit understandings; between the reciprocal relationship between the interpreted and interpreter; between understanding parts and the whole. Understanding deepens by going round the circle again and again.”*

*(Finlay, 2011, p.53)*

Yet, a reader or analyst who has been ‘thrown’ into a parallel world to that of the author, and shares similar experiences (Mitsein), will arguably have an in-depth understanding of the subject matter. Therefore, if a reader already possesses a pre-understanding of the phenomenon with the author of a text, a number of these ‘barriers’ are likely to be overcome as a Mitsein is already shared. Further, a barrier does not exist necessitating interpretation, as the reader and author share this common knowledge and understanding of the phenomenon due to their shared Mitsein. Consideration must be directed, however, to the author’s unique experiences which are not shared by the reader, the author’s Daesin. It is at this point that the reader notices a ‘barrier’ where a shared understanding ceases to exist, and the unique experience of the author gleams through. Here, the reader/analyst can then bracket the commonly shared experiences, allowing the author’s individual experiences to surface. Gadamer, who was heavily influenced by Heidegger, stated that *“the important thing is to be aware of one’s own bias, so that the text can present itself in all its otherness and thus assert its own truth against one’s own fore-meanings”* (1975, p.271-272).

Adopting a Heideggerian approach, I share a Mitsein with the participants as we have all been affected by MND. Adopting Heidegger’s hermeneutical

approach, I am able to look beneath the participants' explicitly used surface language, and get closer to the hidden meaning, thus enabling an accurate '*interpretation*' of their '*phenomenological*' experience, due to a shared Mitsein of MND.

A further consideration, and perhaps more global application of the hermeneutic circle, can be magnified and projected towards the phenomenon itself. Adopting the hermeneutic approach for the analysis of text requires an iterative, non-linear and multi-levelled exploration between the individual parts of the text, in addition to the text as a whole (Smith, 2007).

*"[...] construing the meaning of the whole meant making sense of the parts, and grasping the meaning of the parts depended on having some sense of the whole"*

*(Schwandt, 2014, p.154)*

However, throughout this Chapter, there has been a strong emphasis upon hermeneutics being predominately focussed upon the *individual*. A reader will obtain the experiences from an *individual* person, and comprehend each *individual* word, *individual* sentence, to create an understanding of the *individual* person's experience of the *individual* phenomenon.

*"The foundational law of all understanding and knowledge... [is] to find the spirit of the whole through the individual, and through the whole to grasp the individual"*

*(Ast (1808) cited in Malpas and Gander, 2015, p.178)*

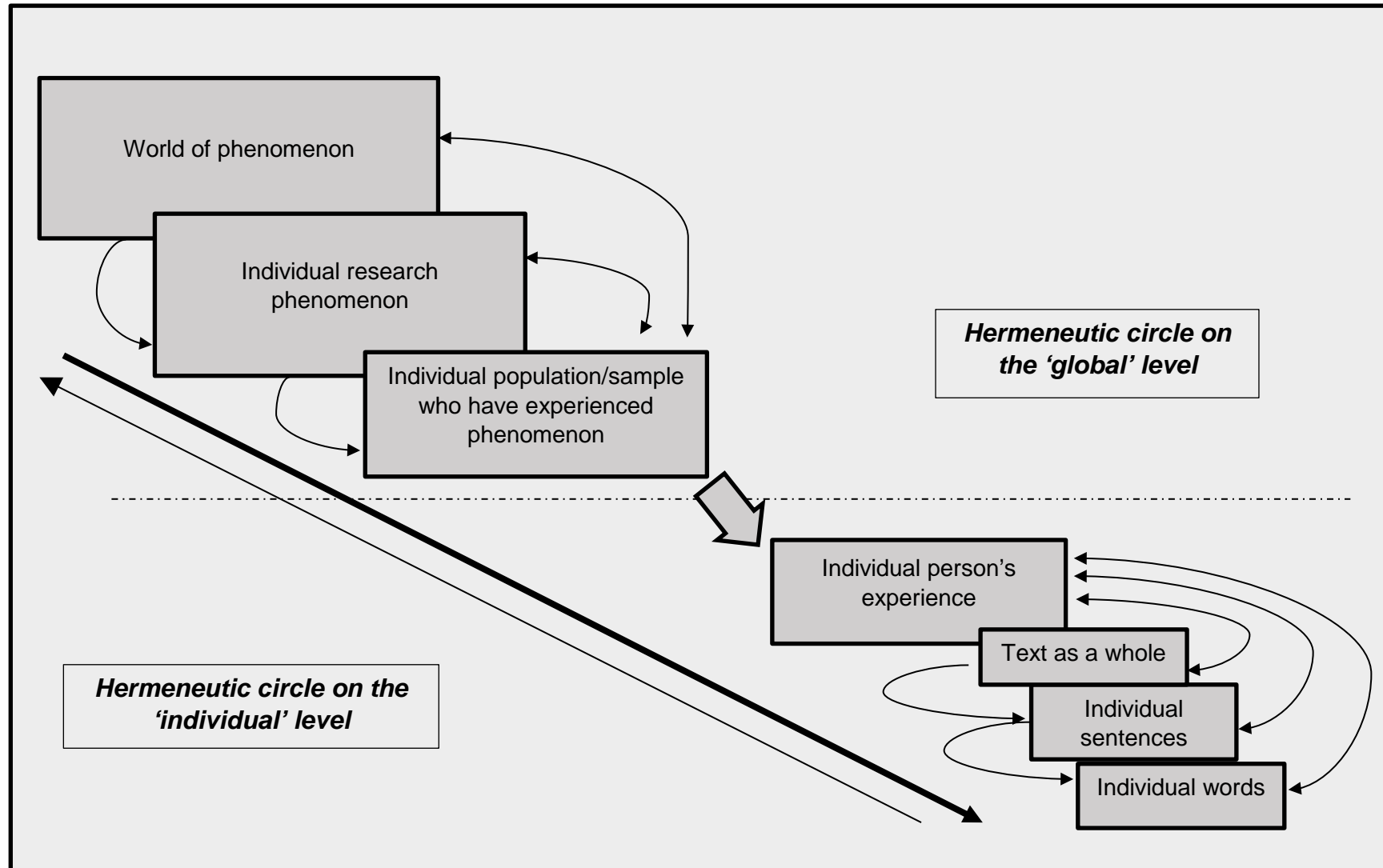
Yet, this can be evolved to a larger scale than that of individual words and sentences creating the individual's experiences of a phenomenon. The overarching experience/research phenomenon can be better understood by

considering an individual author's experiences. Consequently, this notion of a hermeneutic circle to comprehend an individual's experience of the research phenomenon, can be applied on a much larger scale beyond the individual person.

The 'individual hermeneutic circle' provides a researcher with a broad understanding of the individual's world in the form of a whole text. This understanding/experience then becomes more specific through decomposition of individual sentences and words which feedback to the readers overall understanding of the phenomenon. Akin to this, a 'global' hermeneutic circle potentially begins providing a broad understanding/experience of 'being' in the world through our shared Mitsein of living. Similar to the individual level, a researcher will reduce a world of phenomenon (e.g. text as a whole), to a specific research interest (e.g. individual sentences). Following identification of the research phenomenon, a specific sample of people will be recruited (e.g. individual words) (see Figure 6).

Ultimately, then, the hermeneutic circle is notable and reflected on a more global scale than simply the individual person. Instead, this notion of reducing the focus, and cycling back and forth, occurs on a much larger scale (see Figure 6). This means that the individual words/sentences of a single person, can have significant impact upon the reader/researcher's understanding of the research phenomenon on a more global scale. Consequently, through the understanding of an individual author's words, sentences, and whole text on the research phenomenon, meaning will circulate on a number of levels to provide an understanding on the global level.

Figure 6- Diagram of the hermeneutic circle on both individual and global level.



Existential phenomenology was later built upon by Maurice Merleau-Ponty (b.1908-d.1961). Unlike transcendental phenomenologist Husserl, Merleau-Ponty (1962) did not believe it was possible to adopt what he termed a 'God's eye view', and isolate the unique essence of a particular experience. Merleau-Ponty emphasised that the way in which we understand our own experiences, and those of others, is through descriptions and explanations of how we personally have perceived a particular interaction or experience (Langridge, 2007). In the same light as Heidegger, Merleau-Ponty discussed the importance of interpretation of new experiences or phenomenon. However, Merleau-Ponty draws less of an emphasis upon the influences of the world that we are 'thrown' into, and instead describes the importance of our 'embodied' relationship to the world in which we are situated. He also suggests that humans are 'body subjects' and that our understanding and perception of the world is achieved through our bodily experiences as "*the body is the vehicle of being in the world*" (Merleau-Ponty, 1962, p.82).

Merleau-Ponty further theorised that our bodies are vehicles which enable us to perceive our worlds through methods of engagement such as sight, smell or touch. Based on the information collected by our bodies, we then create our understandings and perceptions of the world we are situated in, meaning that our "*lived experience is embodied experience*" (Sandelowski, 2002, p.112). For example, by walking outside and quickly feeling an odd sensation on parts of our body such as our face or hands, we can quickly perceive the weather,

temperature and perhaps begin to make an assumption about the season. All of these inferences are based upon the sensations gained from our bodily engagement which we can then relate to our existing knowledge or past experiences. Merleau-Ponty further suggested that our perception of such experiences can only ever be subjective, for we can never truly know how others will perceive and comprehend a shared experience, due to perception being in accordance with our unique embodied position in the world (Smith, Flowers and Larkin, 2009).

Embodiment is therefore a crucial aspect of this study due to acknowledgment of the importance of how our physical bodies engage with our worlds to give particular meaning to experiences. Within the study, embodiment is notable through acknowledging that the plwMND will be experiencing a decline in physical abilities and, consequently, bodily engagement, as the disease progresses. Therefore, recording videos for a digital legacy provides an opportunity to document the plwMND's embodiment with their world before the disease progresses and physical abilities decline. The concept of embodiment is also notable for the young people who watch and use the digital legacy through the utilisation of senses such as sight and sound. Additionally, the stories, memories and descriptive content that has been recorded in the digital legacy, can also promote cognitive engagement as the young person makes sense of what he/she sees and hears.

#### **4.4 - Idiographic approach**

The terms idiographic and nomothetic were first coined by Windelband in the nineteenth century referring to different forms of evidence-based knowledge (Windelband, 1901). As such, nomothetic approaches to research and knowledge acquisition are concerned with creating findings which are generalisable towards a particular sample of people, theory, or law (Crotty, 1998). Windelband referred to this as 'allgemein' meaning 'common to all' (Robinson, 2012). This approach is often used for quantitative research from which findings are generalised to be 'common to all' for the sample of people who have been tested. Due to this, nomothetic approaches to research can only make generalised and probabilistic claims regarding the individuals who were involved (Smith, 2009). Consequently, a research sample will attempt to recruit participants who are representative of the overall population in order to support generalisability (Coolican, 2009).

In contrast, the idiographic approach aims to focus upon individual experiences of a specific phenomenon with in-depth explanations (Allport, 1937). This approach provides explanatory and descriptive accounts from individuals regarding a specific research phenomenon (Robinson, 2012; Coolican, 2009). Idiographic researchers seek smaller, more homogenous samples of people through purposive sampling methods and recruit people who possess the unique experiences relating to the specific research phenomenon (Smith, 2009; Smith and Osborn, 2007). According to Allport (1937), idiographic approaches provide a recognition to humans as being



'holistic', meaning an individual's complexity and richness of an experience can be incorporated into the research (Breakwell, Smith and Wright, 2012). Consequently, idiographic research does not aim to generate vast quantities of data, but instead is concerned with obtaining quality of information in the form of deeper, richer understandings of the participant's experience (Clarke, 2009a; Snelgrove, 2014).

#### **4.5 - Interpretative Phenomenological Analysis**

Interpretative Phenomenological Analysis (IPA), was conceptualised in the late 20<sup>th</sup> century by Jonathan Smith (1996) and is a distinct methodology with a clear philosophical underpinning, flexible guidelines for data collection, and distinct approach to data analysis. As such IPA is a whole, yet flexible, approach for researchers to explore a cohort's experience of the research phenomenon (Smith and Osborn, 2007; Eatough and Smith, 2006). IPA researchers are interested in how people understand and attribute meaning to an experience or particular phenomenon. Yet, IPA goes beyond establishing inferences based on the descriptive explanations provided by individuals regarding an experience. Instead, researchers adopt a more interpretative engagement with a person's understanding of an event (Langridge, 2007). Due to this, it has become an increasingly prominent methodology across the range of applied health, counselling and clinical research (Hefferon and Gil-Rodriguez, 2011). Therefore, IPA is of particular use when the phenomenon or experience being studied is "*dynamic, contextual and subjective, relatively under-studied and where issues relating to identity, the self and sense-making are important*" (Smith, 2004, p.520).

IPA's epistemology is heavily influenced by phenomenology through attempting to comprehend how an individual has understood and attributed meaning to a particular experience or phenomenon. Consequently, this is how IPA gains the *phenomenological* aspect of its title through incorporation of these key phenomenological principles. These phenomenological values are most notable in IPA through the strong emphasis upon gaining an individual's understanding of a specific lived experience regarding the specific research phenomenon. Yet, unlike transcendental strands of phenomenology, IPA researchers acknowledge that it is not possible to fully bracket our understanding of a phenomenon to be fully objective. Instead, IPA promotes bracketing to consist more of a temporary holding of researcher assumptions, beliefs and judgments about the phenomenon, rather than full separation. This means that IPA researchers will adopt an open attitude and curiosity to viewing the research phenomenon from the new perspective of a participant, without being restricted by their previous/existing assumptions and ideas regarding the phenomenon. Adopting this open attitude in IPA enables a phenomenological process whereby:

*"[...] rather than striving to be unbiased, distanced or detached, the researcher aims to be fully engaged, involved, interested and open to what may appear."*

*(Finlay, 2011, p.23)*

IPA therefore promotes the idea that as a researcher, I am unable to fully 'bracket' and disembodify my own knowledge and memories of MND, caring and bereavement. Instead, I can integrate my knowledge from past experience into an accurate understanding and interpretation of the participant's experience (Gould and Nelson, 2005).

Akin to Heidegger's existential phenomenology, IPA recognises that our experiences, and understanding, of a given phenomenon, is driven and shaped in accordance to the world that we are 'thrown' into. Therefore, a person's understanding of an experience is shaped by a variety of environmental, cultural and social influences, and not by one, singular factor behind their unique comprehension of the experience. Moreover, Heidegger theorises that people are constantly understanding their worlds and events that occur through interpretation according to the worlds that they are 'thrown' into. Consequently, the interpretative aspect of IPA is derived from the interpretative principles that are encapsulated in existential phenomenology.

With IPA, I attempted to establish a connection between the explicit meaning expressed in a participant's description with the more subliminal, and often hidden, understanding of an experience which requires researcher interpretation. Consequently, IPA researchers acknowledge that non-spoken cues are a crucial aspect of understanding a person's experience of the research phenomenon. This is where IPA draws on embodiment, as coined by Merleau-Ponty, through acknowledging the importance of how our physical bodies engage with our worlds to give particular meaning to experiences. Consequently, a person's understanding of an event or experience can be ascertained through more than just their lingual explanation. As discussed earlier, the concept of embodiment suggests that our bodies are vehicles to which our physical interactions and reactions are crucial to our understanding of the world. IPA researchers will therefore draw upon both the cognitive

understanding of an event as described by a person, in addition to the embodied experiences that are felt in reaction to the research phenomenon. For this reason, IPA provides a methodological approach which relies less upon an individual's openly expressed language which may have deteriorated or be affected by diseases (such as MND), and is more focussed upon the individuals experience of the event. Consequently, *"there is scope for IPA research to become less disease- and deficit-focussed, and for participants to be given a chance to express their views about strength, wellness and quality of life"* (Reid, Flowers and Larkin, 2005, p.21).

IPA analysis has an important role in the interpretation of a participant's given experience of the research phenomenon. This is what distinguishes IPA from other phenomenological approaches (Pringle et al., 2011). It is argued that whilst phenomenology uncovers the meaning a person has attributed to a phenomenon, hermeneutics can provide an interpretation of this meaning (Bäckström and Sundin, 2007). Hence, the concept of hermeneutics further exemplifies the interpretative nature of the methodology. However, IPA adopts a reluctance in being able to fully interpret and understand an individual's mind-set and underlying meaning behind the description of the given research phenomenon. Whilst a hermeneutic approach is recognised in IPA, instead, it is emphasised that researchers adopt a more achievable 'hermeneutic approach' when reading and analysing a transcript. Smith (2007, p.5) reinforces this by suggesting that *"[I am] trying to make sense of the words used but I am also trying to make sense of the person who has said those words."*

This hermeneutic approach is further supported when relating to the Heideggerian theories regarding interpretation of text. It is at this point that IPA researchers adhere to the assumption that it is not possible to fully interpret the underlying meaning behind a participant's understanding of what it means to be in the world (Daesin). It is also crucial to recognise that the researcher themselves may have a competing understanding of the Daesin which may cloud the interpretation of the participant's experience. This provides an opportunity for the participant's unique understanding of the research phenomenon to surface, without it being shoe-horned into the researcher's pre-defined assumptions (Spinelli, 2002).

This is where consideration to the hermeneutic circle is prominent in IPA and provides a clear value to the methodology. An IPA researcher is encouraged to interpret text on a plethora of levels to fully comprehend the participants understanding of the event being researched. Through acknowledging the individual's meaning behind each word, how it fits in the sentence, and also, the underlying meaning of the text as a whole, it is possible to get closer to the comprehension of their experience. As such, IPA analysis relies on constant interpretation of how singular words provide context for the text as a whole, whilst rigorously documenting the thought process and justifying its interpretation.

Unique to other hermeneutic approaches, IPA adopts what is known as a 'double hermeneutic'. This is where the participant is trying to make sense of the research phenomenon, whilst the researcher is attempting to make sense of the participant's experience and understanding. It is at this point that the need of accurate interpretation from the researcher is fully comprehended. Consequently, IPA requires the researcher to adopt what is known as an 'interpretative lens' to view the experience from the participant's eyes (Smith and Osborn, 2007).

*"[...] this usefully illustrates the dual role of the researcher as both like and unlike the participant [...] the researcher is not the participant, she/he only has access to the participant's experience through what the participant reports about it, and is also seeing this through the researcher's own, experientially-informed lens."*

*(Smith, Flowers and Larkin, 2009, p.35-36).*

Another identifiable feature of IPA research which is of key importance in the overall methodology is the notion of idiography. IPA is an inductive approach which is concerned with understanding how a particular cohort of people have made sense of and experienced a particular phenomenon (Clarke, 2009). The aim of IPA research is therefore not to create causal explanations or generalisable facts regarding the research phenomenon (Smith and Osborn, 2007). Instead, IPA research is idiographic and concerned with exploring the participants' 'lived experience' (Reid, Flowers and Larkin, 2005). It is therefore argued that *"IPA seeks idiographic accounts of people's views and perceptions [...] The researcher then gathers these accounts to propose a general description of the phenomenon"* (Finlay, 2011, p.140).

This means that IPA seeks to identify the accounts from a small group of participants that have been purposefully sampled due to sharing a common experience with the research phenomenon (Finlay, 2011). Consequently, the researcher does not aim to recruit participants in order to create a representative sample but, instead, will investigate a group of people who have specific life experience with the research phenomenon (Willig, 2013).

I therefore decided that IPA was the most appropriate methodological approach for my research as it attempts to understand the lived experience of participants in a rigorous, yet flexible manner. Additionally, IPA advocates the use of my existing knowledge to utilise a range of interpretative lenses regarding the disease. Consequently, these lenses will enable a clarity of interpretation behind being affected by MND and creating/using a digital legacy.

#### **4.6 - Summary**

In this chapter I have discussed the theoretical concepts which underpin inductive qualitative research, and therefore, this study. Also discussed in this chapter is the philosophy of phenomenology, with specific focus upon existential phenomenology in accordance with theories by Heidegger and Merleau-Ponty. This evolved into a discussion around the philosophical

concept of hermeneutics idiographic approaches to research. I then introduced my chosen methodological approach for this study, IPA, and explored the various theoretical and philosophical concepts which underpin this unique methodology.

The next chapter will outline the research phases before describing, in detail, the methods adopted throughout the study for participant recruitment, data collection and data analysis.



## Chapter 5 - Methods

“I have little patience with scientists who take a board of wood, look for its thinnest part and drill a great number of holes where drilling is easy.”

Albert Einstein (as cited in Frank, 1949, p.350).

The previous chapter explored the theoretical and philosophical underpinnings which have shaped the IPA methodology. This section will provide a description of the methods employed throughout the study. A justification will also be provided for the methods that have been utilised alongside a rationale for the choices made in adherence to existing literature in the field of MND research and IPA methodology.

### 5.0 - Research aim and objectives

The overarching aim of the study was to investigate the views and experiences of creating, or using, a digital legacy with people affected by MND. Subsequently, the research objectives for my study bear strong adherence to the IPA methodology with a focus upon their personal experiences. Each objective is phenomenological in focus, with the open nature attempting to gain deep, rich and explorative understanding of creating, or using, a digital legacy (Smith, Flowers and Larkin, 2009). Therefore, the three research objectives are respectively focussed upon the homogeneity of each participant group.

**Research Objective 1:** Investigate the feasibility, experiences and perceived value of plwMND in creating a digital legacy for a child or young person in their family.

**Research Objective 2:** Investigate the views and experiences of bereaved young people (aged 11-24) using a digital legacy created by or featuring a family member who had MND.

**Research Objective 3:** Investigate healthcare professional, specialist and expert perceptions of the benefits, value, appropriateness, barriers and challenges of digital legacies by people affected by MND.

## **5.1 - Ethics**

### 5.1.1 - Ethical committee approvals

Ethical scrutiny and approvals were sought from research ethics committees. Firstly, approval was gained from the Faculty of Health and Social Care Research Ethics Committee (FREC) at Edge Hill University (see appendix 3). This approval enabled participant recruitment to occur through a variety of online and offline methods which will be discussed later in the chapter. Additionally, FREC approval also incorporated methods of recruitment with the Motor Neurone Disease Association. Upon receiving a favourable outcome, it was necessary to provide the MND Association with documentation to confirm this approval prior to commencing recruitment.

A later revision to this FREC application was made in order to recruit through NHS-run MND Care Centres. Consequently, approvals were sought from the

Health Research Authority for England and Wales, and the National Research Service for Scotland (see appendix 4). In total, ten sites were involved in the recruitment of participants for the study which will be discussed in further detail later in this chapter.

## **5.2 - Participant ethical considerations**

Due to the sensitive nature of the study with a focus upon terminal illness and bereavement, it was necessary to consider a variety of ethical considerations whilst designing the research. Beauchamp and Childress (2013) emphasise four key principles for ethical research; *autonomy*, *non-maleficence*, *beneficence* and *justice*. Whilst these principles formed the basis for designing and carrying out the study ethically, it was also recognised that in-depth, unstructured qualitative research can often raise additional ethical issues that are not always anticipated (Ritchie and Lewis, 2004). Consequently, Webster, Lewis and Brown (2013) provide a broader framework of key ethical considerations to designing and carrying out qualitative research. As such, this framework provided the underpinning ethical considerations throughout the study.

### **5.2.1 - Informed consent**

As with any research, it is crucial that all participants are fully aware of the purpose behind the study and what their participation will involve. This was achieved through study information being provided in a variety of online and offline formats which are fully discussed in the *recruitment* section of this chapter. Crucially, however, providing information about the study in a variety

of formats ensured potential participants could become informed according to their preferences (Gray, 2014). Each of these recruitment methods aimed to raise awareness of digital legacies, and fully inform potential participants of the study. Participants were then able to make an informed choice to establish contact with me to express their interest in the study whereby an information pack was provided (Bryman, 2008). Follow-up telephone or email conversations also provided an opportunity for participants to seek further clarification on the study and pose any outstanding questions. Adopting this approach ensured that participants were fully aware of the study requirements before consenting to participate in an interview, and given ample opportunities to ask any questions that may have arisen. This alleviated any pressure from participants to consent before being fully informed about the study and participatory requirements (Sarantakos, 2013).

It is discussed by Ritchie and Lewis (2004) about the importance of '*a balance in the amount of detail given*' (p.67). Participant information sheets were developed and later scrutinised by a number of experienced researcher colleagues to ensure content, clarity, and appropriate detail (see example in appendix 5). It was also noted that young people involved in the study may have possessed differing levels of reading comprehension due to the potential spread in participant age. In recognition of this sensitivity, the phase two participant information sheets for 11-15 year olds, were trialled with a lay-audience of five 11-15 year olds (Cresswell, 2013). The feedback received endorsed minor amendments to be made to the font, colours used, and the addition of pictures to promote engagement (see appendix 6).

It is recognised that, under common law, all participants aged 16 years and above are able to provide written consent to participate in research (Health Research Authority, 2017). Formal written consent was gained prior to commencing interviews, this also included permission to audio record the interview. In the event of participants being under the age of 16, written consent would have been gained from a parent or guardian (Shaw, Brady and Davey, 2011) (see appendix 7).

Furthermore, the concept of gaining assent from participants under the age of 16 years old was also incorporated into the study design (see appendix 6). Specifically designed assent sheets were developed for younger participants with simplistic wording in accordance with guidance provided by Ford, Sankey and Crisp (2007). This intended to demonstrate a sense of respect and promote autonomy for the younger participant (Rossi, Reynolds and Nelson, 2003). Additionally, Oulton et al. (2016) argue that gaining appropriate assent from younger participants can reduce the likelihood of coercion, establish a sense of trust, and, ensure that voluntary and informed decision to participate in the research is made by them.

Finally, with involvement in the study recruitment from organisations such as the MND Association and NHS-run MND Care Centres, it was imperative that responsible gatekeeper principles were upheld through them being fully informed about the study they were supporting (Gray, 2014). As such, rigorous discussions took place with the Head of Research at the MND

Association, and research leads in each participating NHS site. These formal discussions provided an opportunity to outline the purpose of the study, the requirements of their respective organisation, and the study procedure. Crucially, participants who were identified through the MND Association or NHS-run MND Care Centres, were made aware that existing services and support being provided by the affiliated organisations, would be unaffected by participation in the study.

#### 5.2.2 - Anonymity and confidentiality

It is argued by Webster, Lewis and Brown (2013) *'that researchers should do everything possible to maintain the confidentiality and anonymity of participants in research'* (p.96). Subsequently, anonymity of data and information provided by participants was clearly stated in all participant information sheets, consent and assent forms, with additional verbal reiteration prior to each interview. Participants were informed that both interview data and personal information would remain confidential to myself as the researcher, and my supervisory team. Any data collected from an interview was anonymised, with identifiable features removed, prior to being included in any dissemination documents and resources (Smith, 2009). Each interview was verbatim transcribed by myself prior to being stored on a password protected University server to further uphold participant anonymity and confidentiality.

Additionally, it was outlined to participants that all digital legacies would remain confidential to the participant and their family. The design of the study ensured that the data collected would comprise only of gaining participant experiences and perceptions of digital legacies. This subsequently ensured that I would not be required to see, or obtain, their personal digital legacy thus acknowledging the sensitive and private content.

### 5.2.3 - Protecting participants from harm

Participant harm is a primary concern for researchers and can be experienced on a number of legal, physical, or psychological levels (Sarantakos, 2013). Clearly, with the research topic being highly sensitive, it was paramount to consider the potentiality of participants experiencing psychological or emotional harm. As such, it was necessary to build this into the design of the study through limiting the occurrence of emotional harm whilst discussing terminal illness, death and bereavement. The purpose behind the study and topics to be discussed were explicitly stated in all documentation and communication with potential participants. This meant that people willing to take part were fully informed of the potential emotionality and sensitive nature of topics to be discussed through participating and they freely consented to take part (Bryman, 2008) (see example in appendix 8). It was also clearly stated in both the information sheets, and, verbal briefing prior to starting the interview, that participants could terminate or take a break at any point during the interview. Ritchie and Lewis (2004) also note that:

*'[...] participants may appear comfortable and may disclose information apparently willingly during an interview, but may later regret having been so open. They may also be left with feelings and thoughts stirred up by the interview long after the researcher has moved on.'* (p.68)

In the event of this occurring, I created a 'service support sheet' with suitable organisations signposted according to the phase of the study the participant was involved in (see appendix 5). After gaining permission from services such as MND Connect, Carers Trust and Child Bereavement UK, I was able to signpost these organisations' contact details to participants in the eventuality that they required further support after the interview.

Finally, Cresswell (2013) suggests that harm can be caused through a perceived 'using' of participants whereby an interviewer obtains data without reciprocating the time, effort and knowledge provided by a participant. To reduce the likelihood of this happening to participants, each person interviewed was thanked extensively upon concluding the interview. Some further formal thanks for their participation was also sent via email within 24 hours of data collection. Lastly, upon request, a summary of the study findings was generated and disseminated to each participant, or bereaved family members.

#### 5.2.4 - Protecting researchers from harm

Whilst much of what has been discussed rightly focuses upon the ethical considerations of minimising harm for participants, Webster, Lewis and Brown



(2013) also highlight the importance of researcher safety and wellbeing. At a fundamental level, the action of carrying out fieldwork possesses its own inherent risks which were considered throughout the study. Generally, the interviews took place in the participant's home meaning I was required to travel to geographically diverse locations. As such, it was important to consider my own safety as a researcher whilst collecting data. Accordingly, a University 'safe fieldworker protocol' was followed during each of the interviews (see appendix 9). This involved providing a member of my supervisory team with contact details of the interviewee and the address where the interview would be taking place. Upon arrival at the interview setting, I would inform my supervisor when I was entering, and provide an indicative time of exit. Contact would later be re-established with my supervisor upon concluding the interview and leaving the setting to confirm my safety. In the event of lapsing over the previously agreed time and not re-establishing contact, my supervisor could intervene to ensure my safety.

Due to the personal nature of the study, with my own experience of MND and bereavement, a formal debrief was arranged with a member of my supervisory team upon arrival back at the University. This provided a period of reflection upon how I perceived the interview went, and additionally, discuss any emotional challenges that I may have faced during the collection of data.

Whilst the majority of these debriefs consisted of initial thoughts around preliminary findings, occasionally there would be discussion around aspects of the interview which I found challenging (to be discussed further in Chapter 10). It was also recommended to establish contact with the formal counselling services provided by the University prior to gaining ethical approval. This agreement ensured that, should it be required, I was able to book an appointment with the counselling team and attend a priority appointment.

### **5.3 - Participant recruitment**

A number of internet-based online recruitment methods were adopted throughout the study and summarised below in Figure 7. In addition, a variety of more traditional offline recruitment methods were also utilised which are summarised later in this chapter within Figure 8. Through utilising a number of recruitment methods, it was possible to promote the study to specific populations of people who had an interest in MND. This aided the recruitment of a homogenous sample who possessed the unique experience of being affected by MND and using, or creating, a digital legacy. Each of the internet-based online recruitment methods will be discussed in turn. Following this, attention will be directed towards the variety of more traditional recruitment methods adopted for participant recruitment.

### 5.3.0 - Online methods of recruitment

Throughout the study, I utilised a number of distinct online social networking platforms; *Facebook*, *Twitter*, *forums*, *blogs* and *YouTube*. Each platform provided a method of firstly raising awareness of digital legacies, followed by outlining the study and requesting contact from potential participants. Boyd and Ellison (2008) define social networking as:

*"[...] web-based services that allow individuals to (1) construct a public or semi-public profile within a bounded system, (2) articulate a list of users with whom they share a connection, and (3) view and traverse their list of connections and those made by others within the system."* (p.211)

Whilst each of the aforementioned social networking platforms fall within this broad definition, they were utilised in different ways to aid study recruitment. As such, each social networking platform and the respective approach adopted for study recruitment, will now be discussed and have additionally been summarised below in Figure 7.

*Figure 7- A summary of the online recruitment methods adopted throughout the study.*

### Facebook



- "mndlegacy" Facebook research page created to provide information on the study and enable a signpost for potential participants
- A link to the page was shared amongst other MND/ALS networks on Facebook
- Regular updates about the study were posted to keep followers of the page informed about recruitment and study progression

### Twitter



- Establishing a MND/ALS specific network by connecting with users who were actively engaged with the disease
- Publishing tweets in both text and pictorial form using the topical hashtags #MND and #ALS regarding the study and recruitment

### MND/ALS Specific Forums



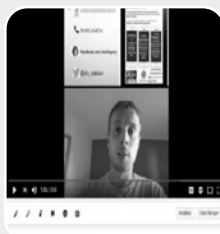
- Upon gaining permission from forum moderators, posts were made in sections 'dedicated to research', or, 'living with the disease'
- Each post contained a brief introduction to myself as the researcher, outline of the study, signpost to software to guide the creation of a digital legacy, and lastly, contact details including the Facebook research page

### MND/ALS & Digital Death Blogs



- After identifying active blogs related to the disease, or, using technology for palliative/bereavement support, i established contact with the author
- Contact consisted of providing an introduction to myself and outlining the study. A request was then made to include details/mention the study in a future blog post made by the author.

### YouTube ( <https://youtu.be/uNWeQmJmFCY> )



- A short 2-minute video was created which outlined the project in order to further raise awareness of the study and call for potential participants.
- Included in the video was a signpost to the Facebook group for additional study information
- A link to the video was then shared on both Facebook and Twitter posts.

### Facebook

Established in 2004, Facebook is one of the most common social networking sites in current times with an estimated 1.94 billion active users every month (Statista, 2017a). At the time of this study, Facebook is free of charge and enables users to create an online profile in which they can upload photographs, connect with friends and post comments to each other's profile pages. Facebook also allows virtual 'groups' or 'pages' in which users with shared interests can network (Ellison, Steinfield and Lampe, 2007). Whilst the use of Facebook as a recruitment tool for health-related research is still in its infancy, strategic posts and tailored advertising can be directed towards a specific demographic of population of people (Kapp, Peters and Oliver, 2013; Whitaker, Stevelink and Fear, 2017). Accordingly, targeted communication to a specific group of users who openly express a shared interest, by being a member of online groups, can be a cost-efficient recruitment method for research (Marks, Wilson and Crisp, 2014). It was therefore possible to identify thousands of Facebook users who were known to have an 'interest' in the disease by being a member of an online MND group.

I therefore created a research Facebook page titled 'Motor Neurone Disease - Legacy Research' with the website address [www.facebook.com/mndlegacy](http://www.facebook.com/mndlegacy) (see appendix 10). In accordance with recommendations by D'Arcy and Young (2012) for utilising Facebook within research for participant recruitment, an 'open' page was created. This page was then personalised to include a brief introduction to myself as the researcher, an outline of the study, and

researcher contact details along with University affiliation. Subsequently, the page provided a resource to inform potential participants through acting as an online signpost, whilst also offering an effective way to update my network of 353 followers on study progression.

Upon identifying established MND groups on Facebook, I sought permission from the group moderators to post brief comments regarding my study and link to the research page. This provided an opportunity to build rapport with the moderator and additionally seek support to allow a recruitment post to be made on the group page, thus eliminating the potentiality of it being perceived as spam and removed (Barratt and Lenton, 2010).

### Twitter

Another common social networking platform is the microblogging website 'Twitter' which was established in 2006. At the time of conducting this study, Twitter is free of charge with an estimated 328 million active users every month (Statista, 2017b). Users publish their own tweets, or, 'retweet' a post from another user, or 'Tweeter', within their network. Each textual tweet is limited to 140 characters which may also include photographs, videos or website links. An important feature of Twitter is the ability to attribute topical keywords or 'hash tags' to a tweet. This enables a tweet to be woven into a relevant conversation or searchable topic. The use of 'Twitter analytics' further provides a detailed log regarding the activity of a published tweet. It was therefore possible to ascertain which tweets gained high levels of interactions with Twitter users allowing subsequent tweets to be tailored accordingly.

After creating my Twitter account (see appendix 11) I began developing my network by searching for the key terms: motor neurone disease, MND, amyotrophic lateral sclerosis, ALS, Lou Gehrig and Charcot's disease. This ensured that my personal network was targeted to a specific population of Twitter users who share a common MND interest. Following this, I began tweeting a brief outline of my study, a link to the Facebook research page, and insertion of #MND and #ALS to weave into existing conversations and topics. It later became clear that tweets which included a picture or image, in addition to the standard text caption, prompted significantly higher interactions from my network of 708 followers. Subsequently, a number of pictorial adverts were created which outlined my study in a more visually attractive manner (see appendix 12).

### Forums

Online discussion forums provide a virtual space to encourage discussion and facilitate knowledge sharing from individuals with a mutual interest, shared experience and/or, specialist skills (Wei et al., 2015). A preliminary internet search was carried out using the keywords: motor neurone disease, MND, amyotrophic lateral sclerosis, ALS and 'forum'. I then ensured that the identified forums were active by screening posts made by forum users. Three online forums were excluded as potential online methods of recruitment due to a dearth of activity within the past 12-months. Consequently, five eligible online forums were identified; *MND Association Forum*, *Building a UK MND Network (BUILD)*, *PatientsLikeMe*, *ALS Therapy Development Institute (ALS-*

*TDI*) and *ALS forum*. After creating an account with each forum, I sought permission from each forum moderator to publish details about the study. In seeking approval from the moderators, who were acting as online gatekeepers, I could ensure membership rules were not breached and adhere to online health research ethical guidelines (Eysenbach and Wyatt, 2002).

Following the receipt of approval from respective forum moderators, I posted a new thread titled '*Research request: children in your family affected by MND/ALS?*' This thread included a brief version of the information included on the Facebook research page. Each post concluded with my contact details and a link to the Facebook research page for additional study details (see example in appendix 13).

### Blogs

The utilisation of online blogs also formed a crucial aspect of social media recruitment for my study. Akin to the procedure adopted by Hookway (2008), and the approach I adopted for identification of appropriate online forums, a preliminary internet search was carried out. The search terms used for this identification were duplicated from those discussed earlier in identifying forums. In contrast, the key term of 'forum' was replaced by 'blog'. A number of blogs were identified to be authored by plwMND, or, to be disease specific (*MND Association Research Blog; Diary of a Dancing Monkey; Speed4Sarah; Simpleasa*). Comparable to the process adopted for screening online forum



eligibility, it was essential to ensure that identified blogs were active through examination of the most recent post made by the user. This screening made it possible to confirm that the author of the blog was still alive meaning an active readership was in existence. Consequently, blogs which displayed no recent posts within the past four weeks, were deemed ineligible for inclusion.

Authors of blogs which met the inclusion criteria were then sent a brief introductory email regarding the study. This would also include researcher contact details and signpost to the Facebookresearch page for additional information. Chiefly, however, this contact with the author provided an opportunity to request the writer to mention my study in a future blog post. This approach facilitated information about the study being included in blogs from the UK, South Africa and USA, thus, further assisting in raising study awareness.

Notably, a number of independent blog authors also initiated contact with me after reading information about my study through the aforementioned social media platforms. Consequently, study information was also included in blogs related to death and dying online (*Time Hath Come Daily; Social Embers News*).

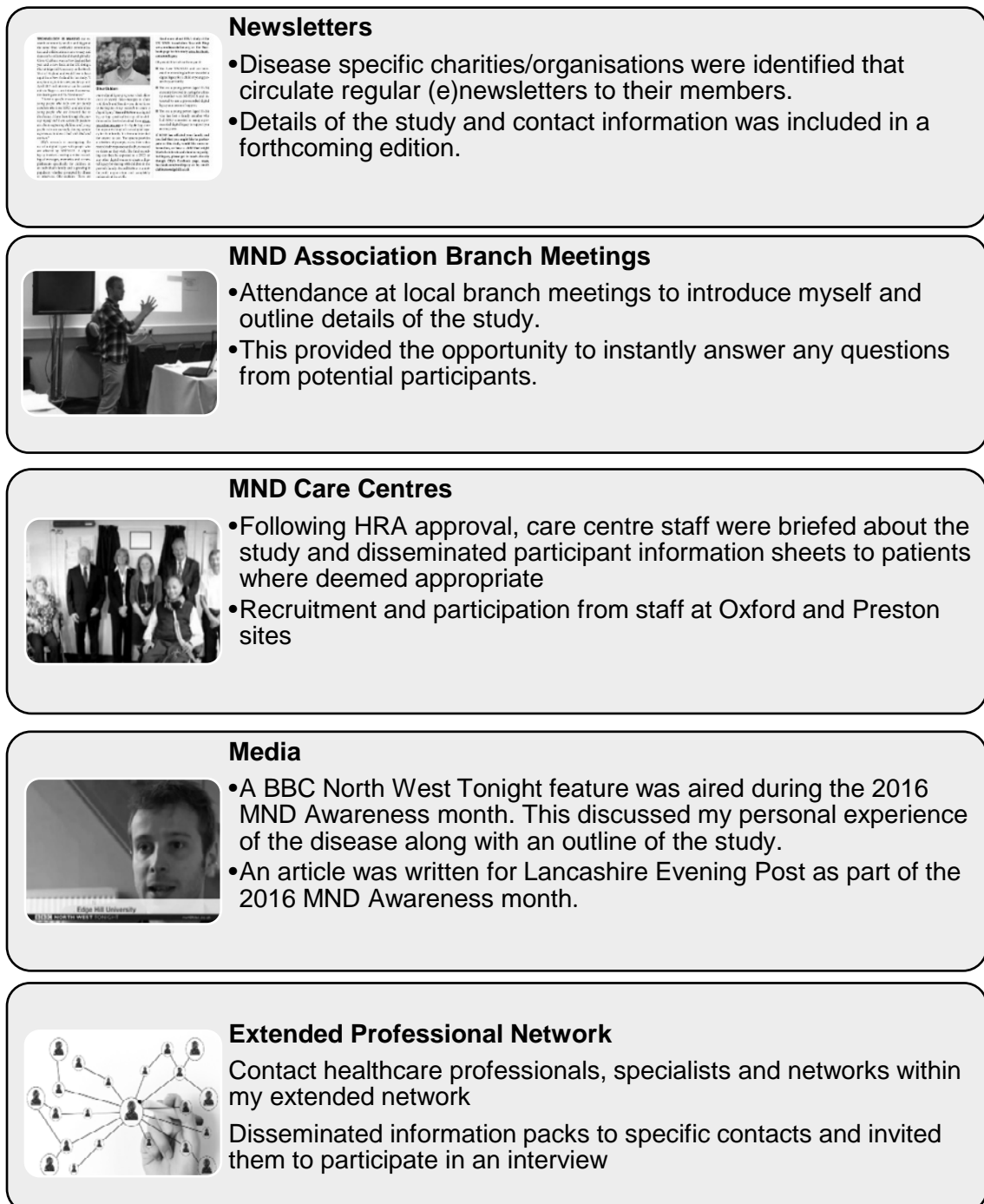
### YouTube

A final method of recruitment using online social media was centred upon the video-sharing platform YouTube. There are approximately a billion users registered to YouTube, with a third of all people using the internet watching videos that have been uploaded to the site on a daily basis (YouTube, 2017). Building upon feedback provided by an online forum user who was living with MND, a suggestion was made to create a short video to outline the study in a more visual form. In response to this feedback, I created a short two-minute video which was then disseminated amongst previously made forum posts, and included in a number of future Facebook updates and Twitter publications.

#### 5.3.1 - Other recruitment methods

In addition to these various online methods adopted to recruit participants to the study, a number of other approaches were also utilised. Similar to the online recruitment methods, each of the other recruitment strategies also had advantages which will be discussed in turn. A summary of these recruitment methods is also provided below in Figure 8.

Figure 8- A summary of other recruitment methods adopted throughout the study.



### Newsletters

A previously successful method of recruitment with the hard to reach MND/ALS population is through publicising in newsletters (Clabburn and O'Brien, 2015). A number of MND/ALS associations and support groups were identified worldwide through an internet search using the keywords [motor neurone disease, MND, amyotrophic lateral sclerosis, ALS] and [association, charity, support group]. A screening process was adopted to ensure that identified associations or groups, had created and circulated either a traditional paper newsletter, or electronic newsletter, within the last six-months. Following this eligibility check, contact was established with the newsletter editor to provide an outline of the study and request the inclusion of a feature, or article, in a forthcoming publication. Articles included in newsletters discussed the concept of digital legacies, an outline of the study and concluded with contact details and signposting towards the Facebook research page.

Consequently, articles were included in a number of MND/ALS association, and support groups newsletters around the world (see Table 2). Additionally, a number of these associations/groups also promoted the study via their online social media platforms.

*Table 2- A summary of the newsletters where recruitment information was published.*

<b>Name of Association/Support Group</b>	<b>(e)Newsletter Edition</b>
ehospice	e-newsletter (18 <sup>th</sup> October, 2015)
George Barton MND Research Trust	Winter, 2015
MND Association (England, Wales and NI)	Spring, 2016 & Winter, 2017
MND Association- Cheshire Branch	June 2016
MND Association of New South Wales (Australia)	e-newsletter (21 <sup>st</sup> October, 2015)
MND Association of New Zealand	Spring, 2015
MND Scotland	Winter, 2015
The Brain Charity	Dec 2015/Jan 2016

### Branch meetings

The MND Association for England, Wales and Northern Ireland run a number of local branch meetings to offer support, guidance and advice to plwMND and their families. Around 100 groups are affiliated to the MND Association and tend to meet on a monthly basis. After seeking and gaining permission from the Head of Research for the MND Association, I established contact with a number of MND Association branches in England. A request was made to visit the branches during forthcoming group meetings to introduce myself and provide a more personable description and outline of the study. Where appropriate, information sheets were disseminated to potential participants who were in attendance at the meetings. Furthermore, it was possible to brief volunteers who coordinate the meetings and supply them with a number of participant information sheets which were disseminated during home visits with plwMND and their families.

This method of recruitment was received well by the MND Association branches. Consequently, a number of additional MND branches and MND special interest groups requested future attendance to discuss the study. Akin to Allen-Collinson and Pavey (2014), these visits were further supported and advertised by the MND Association through frequent online social networking updates from each of the individual branches.

### *MND Care Centres*

A number of MND Care Centres have been developed since 1990 across England, Wales and Northern Ireland (MND Association, 2017b). These care centres are part funded by the National Health Service (NHS) and are situated on NHS sites reviewing patients on a two to three monthly basis. MND specialists and care centre staff provide multidisciplinary advice, guidance and support for plwMND and their families. Recruitment of participants through these care centres has previously been reported as a successful method of sampling within this population and was therefore deemed worthy to pursue for the study (Whitehead et al., 2012). Upon gaining additional ethical approval from the Health Research Authority (HRA), I began recruitment of participants through four NHS sites in England who acted as participant identification centres (PICs) (see Table 3). Approval was similarly sought from the National Research Service which enabled an additional six sites to act as PICs in Scotland (see Table 3). Staff were then encouraged to disseminate participant information packs to any plwMND and/or family members that met the study inclusion criteria. Individuals were then encouraged to establish contact with myself after reading the study information to express a willingness to participate in the study.

It was also necessary to gain HRA approval in order to recruit staff members from the MND Care Centres. Due to their previously expressed interest in the study, Preston and Oxford were identified as fitting sites to act as both a PIC and recruitment site for MND nurses. Study information packs developed specifically for healthcare professionals, specialists and experts were sent to each of these sites. Staff who were willing to participate would then establish contact with me and arrange a convenient time and date for a telephone interview.

*Table 3- A summary of the NHS Trusts and PIC Sites involved in study recruitment.*

<b>NHS Trust - PIC Site</b> (* indicates recruitment site for staff)
<b>*Lancashire Teaching Hospitals Trust- Royal Preston Hospital</b>
<b>*Oxford University Hospitals Trust- John Radcliffe Hospital</b>
<b>NHS Ayrshire and Arran</b>
<b>NHS Dumfries and Galloway</b>
<b>NHS Grampian- Aberdeen Royal Infirmary</b>
<b>NHS Greater Glasgow and Clyde- Queen Elizabeth University Hospital</b>
<b>NHS Lothian</b>
<b>NHS Tayside</b>
<b>Salford Royal NHS Foundation Trust- Salford Royal</b>
<b>The Walton Centre NHS Foundation Trust- The Walton Centre</b>

### Media

An additional method of raising awareness for the study in order to recruit participants was through utilisation of more traditional forms of media. Following extensive contact with the MND Association through attendance at the local branch meetings, conferences and special interest groups, a rapport was built with the media officer at the Association. Consequently, a television

feature was recorded about my study which aired on BBC North West Tonight as part of the 2016 MND Awareness month (see appendix 14). Following this, a newspaper article was also printed for a regional newspaper which described my personal experiences of MND alongside an outline of the study (see appendix 15).

#### *Extended professional network*

A final method to recruit healthcare professionals, specialists and experts, was to utilise my extended network of contacts which had developed throughout the course of the study. An invitation email and participant information sheet was sent to a selection of specialists who were known to possess specific expertise and knowledge in relevant fields. Those who were willing to participate in an interview were then encouraged to establish contact with myself to arrange an interview. In accordance with IPA principles, participant homogeneity was achieved through shared perceptions and experiences of digital legacies with people affected by MND. Furthermore, this approach aligned with maximum purposive sampling methods through recruiting a range of expert participants based upon their specialist knowledge and job role (Saunders, 2012; Cresswell, 2013; Gray, 2014).



## 5.4 - Participants

Whilst larger sample sizes are traditionally considered necessary for empirical research to promote generalisability, in adherence with the idiographic nature of IPA research, I aimed to recruit a smaller number of participants (Reid, Flowers and Larkin, 2005). It is argued that by '*gaining insight into the individual, insight into the whole can also be achieved*' (Pringle et al., 2009, p.21).

With this in mind, it was necessary to recruit a purposive, yet homogenous sample of participants (Smith, Flowers and Larkin, 2009). Participants therefore contacted me in response to one of the many recruitment methods that were adopted throughout the study. This initial contact provided an opportunity to pose any outstanding questions regarding the study, express a willingness to participate and, additionally, provide an opportunity to ensure eligibility in accordance with the participant inclusion criteria (see Table 4). The lower age of 11 years old for bereaved young people was set in accordance with operational development theories (Piaget, 1973). This suggests that abstract concepts such as terminal illness and bereavement can be comprehended and discussed by the young person in rational, structured and logical ways (Griffiths, 2009). The upper age limit of 24 years old was identified to coincide with the increasing number of young people who may have been in further or higher education when the plwMND died.

Table 4- A summary of the participant inclusion criteria.

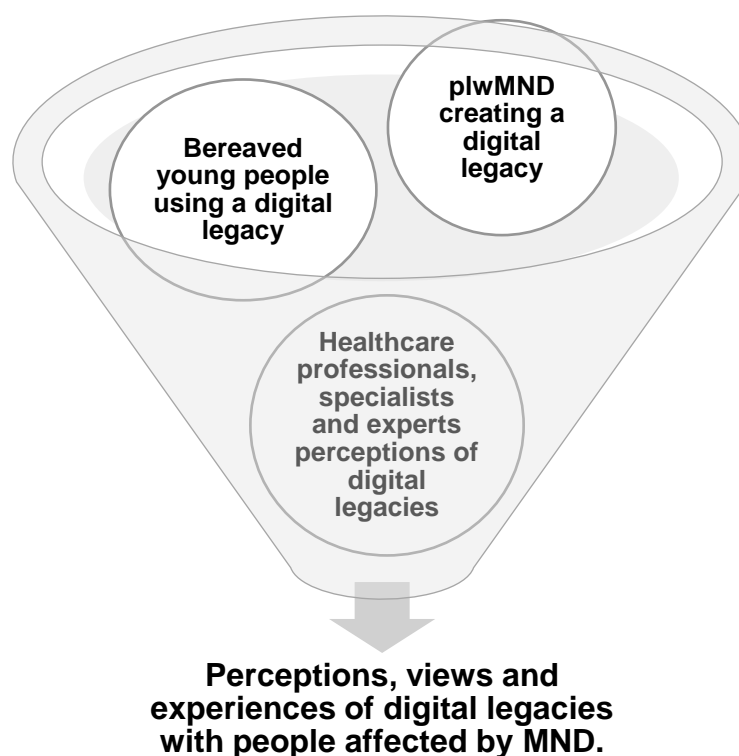
<b>People living with MND creating a digital legacy</b>	<b>Bereaved young people using a digital legacy</b>	<b>Healthcare professional, specialist and expert</b>
<ul style="list-style-type: none"> <li>• Aged 18 years old and above</li> </ul>	<ul style="list-style-type: none"> <li>• Aged between 11 to 24 years old</li> </ul>	Specialists or experts within one or more of the following fields: <ul style="list-style-type: none"> <li>• MND Care (NHS)</li> <li>• Palliative Care</li> <li>• Spiritual Care</li> <li>• Child Bereavement</li> <li>• MND Children &amp; Young people</li> <li>• Child Development</li> </ul>
<ul style="list-style-type: none"> <li>• Confirmed diagnosis of MND</li> </ul>	<ul style="list-style-type: none"> <li>• Bereaved due to a family member dying from MND</li> </ul>	
<ul style="list-style-type: none"> <li>• Created, or, in the process of creating a digital legacy for a child or young person in their family</li> </ul>	<ul style="list-style-type: none"> <li>• Access to a digital legacy made <i>by the person who had MND, or;</i></li> <li>• <i>Featuring the person who had the disease</i></li> </ul>	
<ul style="list-style-type: none"> <li>• English speaking</li> </ul>	<ul style="list-style-type: none"> <li>• English speaking</li> </ul>	
<ul style="list-style-type: none"> <li>• Able to communicate verbally or via alternative methods (ACC or email)</li> </ul>		

Whilst it was likely that participants in the sample would possess unique influential socio-demographic factors, the concept of a ‘fairly homogenous’ sample was pursued (Smith, Flowers and Larkin, 2009; p.56). Whilst Brocki and Wearden (2006) suggest sample sizes in health psychology literature to vary between one and thirty participants, there is recognition that smaller sample sizes are becoming more prevalent. As such, homogeneity between participants was achieved through recognition of shared experiences between a small sample of plwMND creating a digital legacy. This was similarly reflected with the small, yet purposively recruited sample of bereaved young people who shared experience of using a digital legacy following the death of a family member who had MND. In contrast, Smith, Flowers and Larkin (2009) also outline the application of IPA research with larger samples of participants when researchers carefully negotiate ‘convergence and divergence,

*commonality and individuality'* (p.107). In accordance with maximum purposive sampling methods, homogeneity for the larger sample of 20 healthcare professionals, specialists and experts, was achieved through gaining their individual perceptions of digital legacies with plwMND and bereaved young people (Saunders, 2012).

As depicted below in Figure 9, each of the three participant populations would possess unique perceptions and experiences of the research phenomenon. Homogeneity between participant groups was therefore based upon mutually shared perceptions, views and experiences of digital legacies with people affected by MND.

*Figure 9- A visual representation of homogeneity between participant populations.*



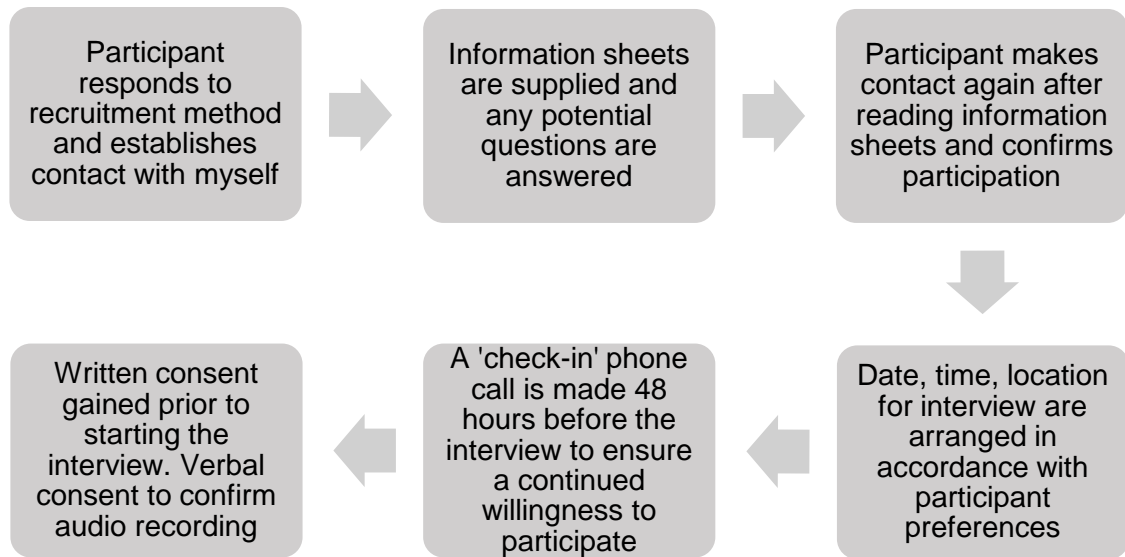
## **5.5 - Research Setting**

Due to the deteriorative nature of MND for participants involved in phase one of the study, alongside the sensitive nature of the interview topic, it was necessary to carefully deliberate over the setting of each interview. In accordance with Warren (2002), participants who were willing to discuss their experiences were given the opportunity to set the preferred time, date and location for the interview to take place. It was crucial for participants to feel comfortable in a setting to promote a sense of safety in disclosing sensitive and personal information that the interview would be focussed upon. Furthermore, by allowing the participant to indicate a time, date and place for the interview to occur, I was able to cause as little disruption to daily routines as possible and reduce a sense of burden and inconvenience to participating in the study (Gray, 2014). This was similarly replicated for healthcare professionals, specialists and experts who were willing to participate in the study. According to participant preference, interviews were conducted either at their place of work or via telephone.

## 5.6 - Data collection

The participant journey and data collection procedure is summarised below in Figure 10 with full details to follow.

*Figure 10- The participant journey and data collection protocol for the study.*



The use of structured or semi-structured interviews is a common method of qualitative data collection within palliative care research investigating patient needs and experiences (Gysels, Shipman and Higginson, 2008; Whiting and Vickers, 2010; Hannon et al., 2016). Similarly, a phenomenological study aims to collect a *'rich, detailed, first-person account of their experiences'* (Smith, Flowers and Larkin, 2009, p.56). Van Manen (2014) argues that phenomenological interviews create highly unique and significant challenges to collecting data for researchers. Whereas many qualitative approaches focus on participants telling the researcher *about* an experience, a phenomenological interview instead requires detailed interpretations, opinions and views of actually *living* the experience (ibid).

With this in mind, an IPA interview is often described as a ‘*conversation with a purpose*’, being driven by the participant who is describing the experience in their own words (Smith, Flowers and Larkin, 2009; p.57). Each interview followed the format adopted by Hanley (2013) who similarly carried out an IPA study with plwMND and their carers. Each interview began with a generic and open question to engage the participant and stimulate the conversational flow. Subsequently, one of two open questions were posed in accordance with the study phase the participant was contributing towards:

- plwMND: “*I am interested in your experiences of living with MND and creating a video-based digital legacy for a child/young person in your family. Please begin wherever you like.*”
- Bereaved young people: “*I am interested in your experiences of being bereaved and using a video-based digital legacy of your family member that had MND. Please begin wherever you like.*”
- Healthcare professionals, specialists and experts: “*I am interested in your perceptions of plwMND creating a video-based digital legacy for a young person in their family.*” / “*I am interested in your perceptions of bereaved young people using a video-based digital legacy created by a family member who had MND. Please begin wherever you like.*”

I rejected the use of an interview schedule with pre-set questions. Instead, I favoured a ‘loose agenda’ which consisted of key topics and areas which I hoped to explore throughout our purposeful conversation (Reid et al., 2005). This ensured that the interview was predominantly driven by the participant meaning their experiences of creating, or using a digital legacy, would be discussed in a depth and logical order that was appropriate for the individual participant. This also promoted a free-flowing conversational feel through

adopting a reflexive dyadic interview (Jones, Adams and Ellis, 2013). I did, however, refer to the prompt sheet on occasions when the conversation had naturally ceased to flow (Biggerstaff and Thompson, 2008). This ensured that previously identified areas of key importance would be discussed throughout our purposeful conversation (Smith, Flowers and Larkin, 2009). If, during this referral, I felt that a specific prompt on the agenda may induce additional information from the participant that was previously touched upon, or aid my understanding of their experience, I would appropriately reintroduce the topic using explorative probes such as:

- *“Earlier you mentioned about [topic/experience/perception]. I was wondering if you could tell me a bit more about that...”*
- *“One of the things that you touched on was about [topic/experience/perception]. This is something that I’m really interested in and wondered if you could tell me a bit more...”*

Akin to IPA research conducted by Hanley (2013), I also drew upon the experiences that had been discussed by participants in previous interviews, and raised them with subsequent participants. This promoted a sense of the interview process evolving in accordance with my growing knowledge of the research topic, prompted by an increased understanding of participant experiences due to previous interviews. Such evolution of the interview process was clear through the type of questions being posed to participants:

- *“One of the things that has been mentioned during interviews with other participants, is the idea of [topic/experience]. I was just wondering what your experience was and what it was like?”*
- *“Some of the other people/plwMND/bereaved young people that I have interviewed have talked about [topic/experience/perception]. I wondered if you had any thoughts on this?”*

Often this type of question was noted to be effective in opening up dialogue when exploring highly sensitive issues. This approach seemed most effective when discussing topics such as death and dying with participants involved in phase one of the study. It is argued that externalising questions by attributing sensitive topics to 'other participants', may provide a sense of relief to some people and provide validation for inner thoughts and feelings (Carey and Russell, 2004).

Whilst this approach of a participant led interview contradicts some existing literature on carrying out qualitative interviews (Patton, 2002; Gray, 2014), it supports IPA through promoting the interview as conversational and driven by the participant (Smith, Flowers and Larkin, 2009). This was further evident throughout the data collection process when participants would occasionally ask questions about my own experiences of the disease. Not only did this reinforce the aim of creating a conversational feel for the interview, but also assisted in building rapport with participants through reciprocal sharing of personal experiences and self-disclosure (Zink et al., 2016).

Each interview was audio recorded which ensured that my focus, as the conversation facilitator, could be dedicated to the participant, rather than scribing lengthy notes (Smith, 2009).



## **5.7 - Data management**

Each interview was subjected to verbatim transcription and anonymised by removal of any identifiable data which was replaced with pseudonyms. Hard copies of the data, such as completed consent sheets, were stored in a lockable secure research office at Edge Hill University and later destroyed after being scanned and saved on a password protected server at the University. Similarly, audio-files of the interview were electronically stored on the same password protected University server for the duration of the study, and destroyed upon being awarded the PhD. The storage of these audio-files enabled an audit process of cross-checking sections of the written transcripts alongside the corresponding audio-file by members of my supervisory team, thus ensuring written accuracy and promoting study rigour (Smith, Flowers and Larkin, 2009). Consequently, the paper and electronic files used for the study were accessible only to myself and my supervisory team which were handled, processed, stored and destroyed in compliance with the Data Protection Act 1998. In accordance with University protocol, anonymised data and approval letters will be kept for a period of ten years by members of my supervisory team who will act as data guardians.

## **5.8 - Data analysis**

The existing IPA literature does not provide a singular method or rigid framework for the analysis of data (Smith and Osborn, 2007; Wagstaff and Williams, 2014). Instead, IPA offers a flexible set of guidelines which researchers are encouraged to adapt in accordance with their research and

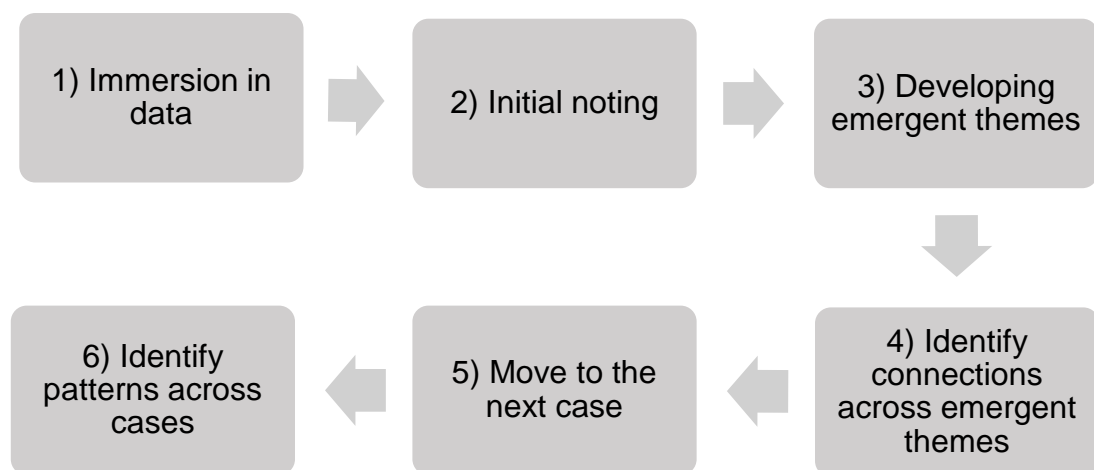
overarching objectives (Pietkiewicz and Smith, 2014). However, Smith, Flowers and Larkin (2009) argue that common processes and principles are ubiquitous to all IPA approaches. As such, *'moving from the particular to the shared, and from the descriptive to interpretative'* (p.79), is a key process involved in IPA. Whilst additionally, researchers are striving to understand the *'participant's point of view, and a psychological focus on personal meaning-making in particular contexts'* (p.79). It was therefore crucial to ensure that the methods and approaches adopted during the analysis of data, honoured both characteristics. Whilst inductive in nature, it is argued by Reid, Flowers and Larkin (2005) that good IPA requires the researcher to find a 'balance' between both the *'emic'* and *'etic'* positions. The former, emic position, endorses an IPA researcher to adopt an insider perspective through careful reading, hearing and understanding the world through the lens of the participant. In contrast, the etic position of the researcher requires the adoption of an 'outsider' lens whereby the participants story, understanding, and experience, is interpreted in regards to the research topic. It is this which highlights the concept of the 'double hermeneutic' in IPA, whereby researchers attempt to make sense of how the participant has experienced, understood and attributed meaning to the research phenomenon (Smith, Flowers and Larkin, 2009).

*"The participant is trying to make sense of their world. The researcher is trying to make sense of the participant trying to make sense of their world"*

*(Smith and Osborn, 2007, p.54).*

The idiographic commitment in IPA is also evident throughout the data analysis process which is summarised below in Figure 11. Each participant's transcript is analysed singularly, thus allowing their unique and individual perspectives of the research phenomenon to surface (Reid, Flowers and Larkin, 2005; Willig, 2013). Only once all cases have been analysed independently, does the IPA researcher begin to tentatively propose general statements and emergent patterns which tie each of these single cases together (Eatough and Smith, 2008; Pietkiewicz and Smith, 2014). Consequently, the analytical process is multifaceted which required myself, as the researcher, to engage deeply with each case before iteratively attempting to analyse, interpret and code the data (Smith, Flowers and Larkin, 2009).

*Figure 11- A summary of the data analysis process.*



#### Step 1: Immersion in the data

The first stage of IPA requires an immersion in each participant's data in order to actively engage with their understanding and experience of the research phenomenon (Smith, Flowers and Larkin, 2009). This initially occurred through

conducting each interview and personally creating verbatim transcripts which enabled a deep familiarisation with the data (Gray, 2014). I then engaged with the data through repeated readings of the transcripts in full whilst also listening to the audio of the interview. This process allowed me to add additional punctuation and note prominent features on pronunciation, hesitation or specific word emphasis (Pietkiewicz and Smith, 2014).

Lastly, I proceeded to reduce each participant's transcript down to omit superfluous data which was not directly relevant to my research topic or question (Spencer et al., 2013). I was aware that complete removal of data may have restricted my later in-depth data analysis, which may have benefited from contextualisation using the data that had previously been deemed superfluous. I therefore highlighted sections of direct relevance in red whilst superfluous data remained in black. To enhance rigour, copies of these anonymised and colour coded transcripts were disseminated to my supervisory team who acted as independent auditors and verified the relevance of each coded section during this preliminary coding (Smith, 2011; Silverman, 2013; Gray, 2014).

### Step 2: Initial noting

As suggested by Pietkiewicz and Smith (2014), the steps offered for data analysis in IPA can often merge somewhat organically. My initial noting arguably occurred during my phase of immersion in data where I colour coded sections of the transcripts to omit superfluous data. I would also make rough

notes by hand on a separate piece of paper outlining preliminary ideas, questions or concepts that occurred to me whilst reading the colour coded sections (Wagstaff and Williams, 2014). I then decided to import each transcript to NVivo11<sup>®</sup>, a computer software package dedicated to the analysis of qualitative data. Whilst NVivo11<sup>®</sup> did not analyse the data for me, it provided an efficient and user-friendly platform to organise data during analysis whilst retaining the richness and complexity of each participant's spoken word (Wong, 2008). Of further benefit was the ability to gradually import one transcript at a time which promoted an iterative process to analysing the data in accordance with idiographic IPA principles (Bringer, Johnston and Brackenridge, 2006).

In keeping with the hermeneutic element of IPA, I would then adopt a meticulous line-by-line approach highlighting sections, sentences, phrases and words that I deemed pertinent. Due to using NVivo11<sup>®</sup>, it was possible to create and organise a number of detailed notes and labels for sections of the transcript that I had explored. This process was extremely time-consuming and required a significant level of engagement with each participant's transcript. Due to a high level of immersion and familiarisation with the data, I found it possible to 'hear' the participant's voice which enabled me to retain the richness and sentiment of each participant's experience. Consequently, my focus during this stage of the analysis was in keeping with IPA principles by exploring, describing and understanding each participant's unique perceptions and experiences (Smith, Flowers and Larkin, 2009).

### Step 3: Developing emergent themes

During this stage of the analysis, I shifted my focus slightly and utilised my 'interpretative lens' through drawing upon my personal experiences and knowledge. I therefore began to interpret, refine and organise the explorative notes that I created in the previous step (Pietkiewicz and Smith, 2014). Where appropriate, I began to apply psychological concepts and developed emergent themes which best captured the essence of the previously created explorations (Willig, 2001). These emergent themes were known as 'codes' in NVivo11<sup>®</sup>, and at this stage, were somewhat tentative being frequently amended as I progressed through the transcript with new concepts and themes regularly emerged.

### Step 4: Making connections across emergent themes

I then began to map connections, patterns and relationships between the numerous emergent themes that I had previously developed (Smith, Flowers and Larkin, 2009). My aim at this stage was to develop and group clusters of conceptually related emergent themes, which would later form overall super-ordinate categories (Biggerstaff and Thompson, 2008). Some emergent themes were dismissed due to a weak evidence base or due to not fitting well with the emerging structure of the superordinate categories (Pietkiewicz and Smith, 2014). On occasions, it was also necessary to create subthemes to assist with categorisation, or alternatively, rephrase the super-ordinate theme to better capture the 'essence' (Willig, 2013).

#### Stage 5: Next case

The previous four steps were then repeated for each participant through immersion in their transcript, making initial notes, developing emergent themes and searching for connections. In keeping with the idiographic approach underpinning IPA, I ensured that each case (or transcript) was analysed for its own merits and resisted being influenced by previous cases (Smith and Osborn, 2007).

#### Stage 6: Patterns across cases

The aim of this final stage of analysis was to identify significant and recurring themes across the dataset (Smith, Flowers and Larkin, 2009). Unsurprisingly, each participant had a number of unique emergent and super-ordinate themes which reflected their individual perspectives and experiences. This challenge was alleviated through use of NVivo11<sup>®</sup> to produce outputs for each participant detailing their unique set of analytical codes and frequency of recurrence (see example in appendix 16). It was then possible to create theme specific outputs using NVivo11<sup>®</sup> in order to identify patterns across the whole dataset which formed overall superordinate and ordinate themes (Wagstaff and Williams, 2014). In contrast to Biggerstaff and Thompson (2008), who suggest to create a 'master list' or table of themes, I chose to create compilations of participant quotes for each theme using NVivo11<sup>®</sup> (see example in appendix 17). This is suggested to enhance rigour through providing transparent evidence for the level of recurrence for each identified theme alongside participant quotes

(Silverman, 2013). Finally, it was then necessary to synthesise the various themed outputs into a narrative which not only described unique participant experiences, but also conveyed my own interpretation of the data (Smith, Flowers and Larkin, 2009). This inductive approach to IPA research therefore goes beyond simply retelling participant experiences and creating generalisable conclusions. Instead, emphasis is directed towards analysing findings in accordance with my existing knowledge as the researcher (Brocki and Wearden, 2006).

## **5.9 - Validity and reliability**

The concept of validity and reliability in research are crucial for both quantitative and qualitative research methodologies (Gray, 2014). Yet some qualitative researchers debate the appropriateness of generic criteria to assess the quality of *'good sound research'* from different contexts and disciplines (Coolican, 2009, p.576). Instead, it is argued that the validity of qualitative research is measured through considering a number of measures to ascertain credibility and authenticity (Sarantakos, 2013). In contrast, qualitative researchers are less concerned about the measurement of reliability due to the focus of research being on a *'particular, possibly unique, phenomenon or experience'* (Willig, 2013, p.24). As such, qualitative researchers are seeking the authenticity and credibility of findings, rather than focussing upon generalisability (Sarantakos, 2013).



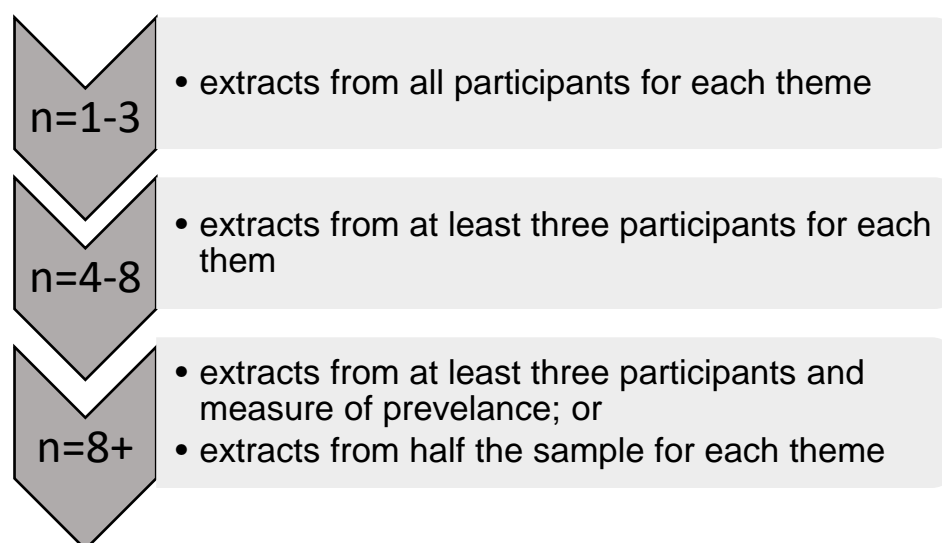
While there are a number of checklists and criteria to assess the quality of qualitative research, Smith, Flowers and Larkin (2009) advocate the use of Yardley's criteria (2008). This provides four broad areas of consideration which will be described in Chapter 11 with consideration to the current study. However, Smith, Flowers and Larkin (2009) also emphasise the importance of promoting rigour through use of an independent audit. This involves careful organisation of data to create a '*chain of evidence that leads from initial documentation through to the final report*' (ibid, p.183). In other words, independent auditing provides a transparent and systematic account of how findings have been generated (Coolican, 2009). This was primarily achieved through use of NVivo11<sup>®</sup> which provides an electronic 'paper trail' of data analysis and interpretation (Smith, Flowers and Larkin, 2009).

Rigour was also enhanced through a series of 'mini audits' conducted by members of my supervisory team (Smith, Flowers and Larkin, 2009). All transcripts and preliminary emergent themes generated from the interviews with plwMND and bereaved young people were sent to my supervisory team to be audited. Similarly, all 20 annotated transcripts from the healthcare professionals, specialists and experts were chronologically numbered before selecting ten to be audited using an online random-number generator. Feedback was then provided regarding the initial notes, themes and concepts that I had begun to develop. This ensured that my initial annotations

possessed validity and, where appropriate, offered me guidance and support in developing specific areas or concepts of particular importance (Smith, Flowers and Larkin, 2009). This approach negated the need to employ 'member checking' which does not lend itself to IPA studies involving more than one participant whereby an amalgamation of accounts is being pursued (Larkin and Thomas, 2011).

An additional measure of quality within IPA research is regarding the provision of adequate evidence for each theme. This requires careful negotiation between presenting an appropriate number of participant quotes for each theme, whilst also providing sufficiently in-depth interpretations of the data (Hefferon and Gil-Rodriguez, 2011). It is therefore necessary to be '*sufficiently selective about what is included*' to reduce a sense of readers feeling '*swamped by the evidence*' (White et al., 2013, p.373). Whilst there are no clearly defined rules in IPA research regarding the quantity of participant quotations and depth of interpretation included for each theme, guidance has been provided by Smith (2011). As depicted in Figure 12 below, one aspect of quality in IPA research is guided by the provision of sufficient evidence according to the size of the sample. I therefore ensured that data was extracted equally from across the dataset and adhered to this guidance throughout the synthesis and writing up of findings.

Figure 12- Quality evaluation guide for IPA research (Smith, 2011).



Similarly, quality in qualitative research can also be enhanced by comparing, contrasting, and verifying the views of participants through a process of sampling triangulation (Sarantakos, 2013). As suggested by Coolican (2009), this provides a way to *'present multiple and diverse perspectives that add up to a fuller picture'* of the use of digital legacies with people affected by MND (p.578). This is evident through interviewing distinct groups of plwMND, bereaved young people and healthcare professionals, specialists and experts. Whilst each participant group was homogeneous in their views, perceptions and experiences, a deeper understanding of the research topic was gained when comparing and contrasting data from multiple participant populations (Wu et al., 2016).

A final way in which rigour was enhanced throughout the study was through engaging in a process of reflexivity. A key element of being a qualitative researcher involves adopting *'an attitude of self-awareness and active reflection'* upon how personal *'baggage'* can shape and mould the research

(Eatough and Tomkins, 2013, p.259). As mentioned in the preface of this thesis, it is clear that I approached the study with a great deal of history which influenced my role as the researcher. As described by Shaw (2010), there are two practical ways in which researchers can adopt a reflexive attitude. Firstly, an audit trail was created through analysing data using NVivo11® which documented the transition from raw data to interpreted findings. Secondly, I kept a reflexive diary throughout the duration of the study in which I documented personal notes regarding specific decisions, problems and challenges I encountered (Eatough and Tomkins, 2013). This process of reflexivity reinforces Husserlian concepts on how '*we should go back to the thing itself*' (Smith, Flowers and Larkin, 2009, p.33). As discussed later in the thesis (Chapter 10), I explicitly reflected upon how my existing knowledge and experience of MND had influenced my interpretations of data, whilst also providing comment upon how the research has changed my preconceptions (Willig, 2013).

## **5.10 - Summary**

In this chapter, I have discussed the various online and offline methods of recruitment that were adopted throughout my IPA study followed by outlining the data collection procedure. This has involved discussion of the various ethical considerations that were deliberated throughout the designing and implementation of the study. Finally, an overview has been provided of the various steps adhered to during the process of data analysis. The next chapter will present a narrative synthesis of the findings generated from this data analysis process.

## **Chapter 6 - Findings: the experiences of plwMND creating a digital legacy**

“Everyone must leave something behind when he dies, my grandfather said. A child or a book or a painting or a house or a wall built or a pair of shoes made. Or a garden planted. Something your hand touched some way so your soul has somewhere to go when you die, and when people look at that tree or that flower you planted, you’re there.”

Ray Bradbury (1920-2012)

In this chapter I will present findings from the interviews conducted with plwMND regarding their experiences of creating a digital legacy for a child or young person in their family. I will begin by providing an overview of the sample before offering a short biographic narrative for each participant.

### **6.0 - Sample and data collection**

As described in the recruitment section in Chapter 5, participants were recruited from across England. Digital legacies had been created by plwMND in a variety of forms (e.g. diary, biography, story, video biography) to be specifically given to a child in their family. Due to the broad recruitment strategy and the use of various dissemination approaches adopted for the study, it was not possible to definitively record how many plwMND were supplied with information packs. However, six plwMND were sent study

information through Facebook, two through Twitter, and seven plwMND were emailed information in response to newsletters, blogs, forums and the YouTube video. Lastly, 17 hard copies of information packs were given to plwMND during visits to local MND Association branch meetings.

A total of four plwMND were interviewed for this part of the study and provided with a pseudonym. This sample size is in accordance with IPA principles regarding the recruitment of small, yet homogenous, groups of participants (Smith, Flowers and Larkin, 2009). Furthermore, this number reflects the relatively low incidence of MND in the UK, alongside an awareness that only a small proportion of plwMND may have young people in their family to warrant the creation of a digital legacy.

Of the four participants, one named John, requested a second follow-up interview upon fully finishing his digital legacy. In addition, Charlie requested that his wife be present throughout the interview to assist with any issues of understanding his deteriorated speech. Consequently, additional input or clarification on his experience of creating a digital legacy was also provided by his wife during the interview. All interviews were conducted face-to-face in the participant's home, which was their preference. Poignantly, the interviews were short in duration which ranged between 33 to 49 minutes. Whilst it is acknowledged that short interviews are somewhat uncommon for IPA research, it should be noted that participants suffered from significant lethargy as a result of disease symptomatology. As such, the duration of the interview

was dictated by the individual participant's willingness and ability to continue speaking to me. In order to maximise the anticipated limited time for each interview, participants were encouraged to engage in a period of reflection prior to the interview about their experiences of creating a digital legacy. This promoted a sense of efficiency for each interview, with participants being fully engaged providing considered responses during our 'conversation with a purpose' (Smith, Flowers and Larkin, 2009, p.57).

In accordance with the idiographic principles which underpin IPA research, a synopsis of biographical information regarding each participant and their digital legacy is provided below and summarised in Table 5 (page 139) (Smith, Flowers and Larkin, 2009).

### Alice

Alice lived in the Midlands with her son, partner and step-daughter. Before being diagnosed with MND in April 2015, at the age of 44 years old, she had worked as an employment officer with adults who had learning disabilities. Alice had learnt about the study through reading a post on an online forum and arranged to be interviewed in May 2016. During the interview, Alice described how she was now unable to walk and had limited use of her hands due to progression of the disease. She considered her digital legacy to consist of various text messages and voicemails that she had sent to her son and step-daughter since becoming ill. She also described how she downloaded pictures and quotes from the internet which she compiled into a scrapbook with help from her partner and step-daughter. Alice's video legacy was created as part

of a local hospice initiative to create an educational resource for staff members regarding MND and promoting family life whilst living with the disease. Throughout this video, she spoke of her love for parenthood and the happiness to be still able to contribute to her children's lives. Alice hoped that this video would be watched by her children in the future and inform them of how she perceived her parental role and what she thrived upon as a mother.

### Charlie

Charlie was diagnosed with MND in early 2014 and lived in the north-west of England with his wife. He had one son and a daughter who had died approximately two years before I interviewed him in July 2016. Charlie was now in his fifties but had once been a stay-at-home parent for his children and nephew. Once they had grown up, he then became a driving instructor before becoming ill. Throughout much of his adult life, he had also been the lead singer in a locally renowned band. In addition to this, Charlie had also been a pub quiz-master for well over twenty years and a member of the local motorcycle club. He was therefore well known in the area and thrived upon performing and *'fighting the jokers off once they'd had a drink'* with his witty come-backs. Charlie had learnt about the study through his local MND care centre and arranged an interview to discuss the video stories he had recorded for his future grandchildren and great nieces and/or nephews. Due to progression of the disease, Charlie used a ventilator, had very limited movement of his arms, and was confined to his bed where the interview took place. He later died in January 2017, three years after his diagnosis.



### John

John was diagnosed with MND in 2012 when his son was just one year old. Whilst he was now living in the north-west of England, John had previously been an award-winning wine journalist. He had therefore travelled all over the world for his work and spoke fondly of his time in Latin-America. John was in his mid-forties and had learnt about the study through reading an advert in a national charity newsletter and arranged an interview in February 2016. He had begun to record a number of digital legacies for his son such as a video diary, online blog and use of structured online video-legacy software. Due to not fully completing his digital legacies at the time of this interview, John had requested that I revisited him at a later date when he had finished his recordings. I therefore arranged to interview him again in September 2016 where the follow-up interview was conducted.

### Tommy

Before his diagnosis in the middle of 2013, Tommy had been a trainer for a technical company in the Midlands and a black belt in karate. At the time of the interview in May 2016, Tommy was 44 years old and lived with his wife, son (aged seven) and daughter (aged four). He had lost the ability to walk, had limited use of his hands, and had noticeable deterioration of speech. Tommy had learnt about the study through the research page I had created on Facebook (see appendix 18). He made contact with me and expressed his interest in participating through commenting upon a recruitment post that I had uploaded. At the time of the interview, Tommy had finished creating his digital legacy using structured online video-legacy software and was close to finalising this by saving to DVD.

*Table 5- A summary of participant and digital legacy characteristics*

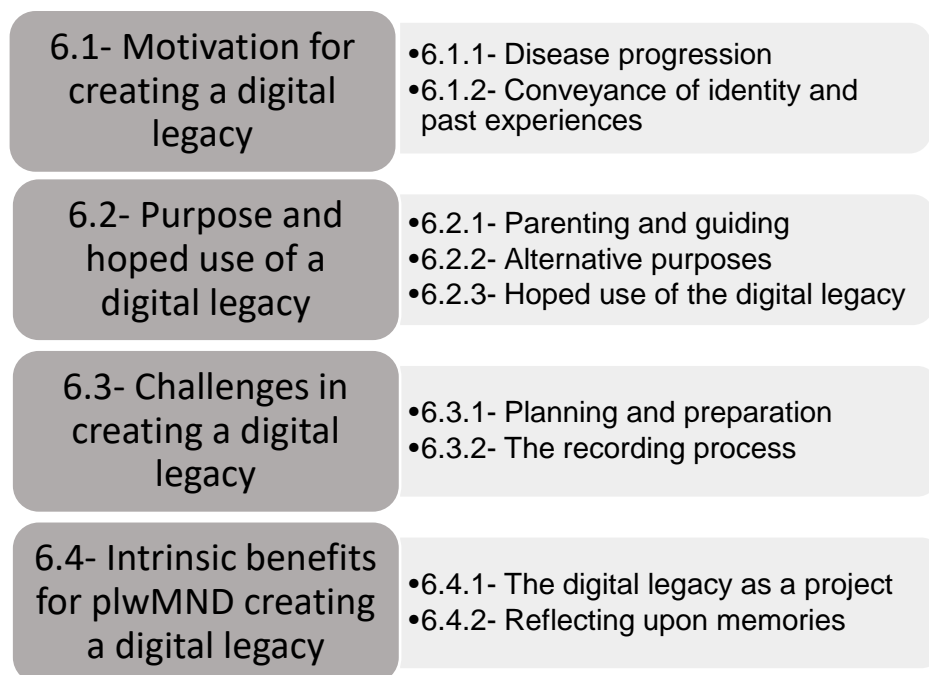
Pseudonym	Received MND diagnosis	Type of digital legacy	Intended audience of digital legacy	Participant location	Method of recruitment	Date of interview	Duration of interview
Alice	Mid-2015	<ul style="list-style-type: none"> <li>• Mobile phone texts &amp; answer phone messages</li> <li>• Downloaded material from the internet</li> <li>• Educational video resource for a local hospice</li> </ul>	Son and step-daughter	Midlands	Online forum	May 2016	49 mins
Charlie	Early-2014	<ul style="list-style-type: none"> <li>• Video story &amp; personal messages</li> </ul>	Future Grandchildren and great niece/nephew(s)	North West	NHS MND Care Centre	July 2016	33 mins
John	Mid-2012	<ul style="list-style-type: none"> <li>• Video diary</li> <li>• Online blog</li> <li>• Digital legacy software</li> </ul>	Son	North West	Charity newsletter advert	February 2016 September 2016	38 mins 37 mins
Tommy	Mid-2013	<ul style="list-style-type: none"> <li>• Digital legacy software</li> </ul>	Son and daughter	Midlands	Facebook	May 2016	49 mins

### 6.0.1 - Analysis

All interviews were transcribed verbatim by myself before undergoing analysis in accordance with the IPA principles described in the previous chapter (Smith, Flowers and Larkin, 2009). This included auditing of transcripts and preliminary themes by members of my supervisory team. As such, anonymised interview extracts are presented alongside analytical interpretations which best exemplify the superordinate and ordinate themes that were generated during analysis.

In total, four superordinate themes and nine subsidiary ordinate themes were developed in accordance with Smith's quality evaluation guide for IPA research (Smith, 2011, page 132). Themes were therefore prevalent in all participant cases and summarised below in Figure 13 to highlight the relationship between superordinate and subsidiary themes.

*Figure 13- A summary of the superordinate and ordinate themes generated from the interviews conducted with plwMND.*



## 6.1 - Motivation for creating a digital legacy

A key theme identified throughout the interviews with plwMND was that there was not a single motivation to create a digital legacy for a young person. Consequently, motivation was attributed to two distinct ordinate themes of *disease progression*, and *conveyance of identity and past experiences*.

### 6.1.1 - Disease progression

All four plwMND, from the five interviews, commented on their motivation to create a digital legacy being attributable to being diagnosed with MND and acknowledgment of their inevitable physical decline.

*[...] what started it [digital legacy] off, very soon after being diagnosed, I kind of knew that the clock was ticking and I didn't know, because it is a bit of an unknown with MND, you don't know how fast it's going to progress.*

*(John, interview 1: lines 702-211)*

In John's case, the process to begin creating his digital legacy was stimulated by the unknown timescale for his disease progression. John mentions '*that the clock was ticking*' which implies an awareness that his physical ability to create his legacy would be diminished in the future. Notably, he quickly shifts from discussing the concept of time with '*the ticking clock*', to highlighting that there is an '*unknown with MND*'. As such, John uses the progression of time as a metaphorical tool to represent the physical progression of the disease.

John later explained that progression of MND not only acted as a stimulus to begin recording his legacy, but also acted as motivator to continue recording videos for his son once he had started.

*And I know, you know, that I'm lucky that I've got my voice because, as I say, that's kind of pushing me forwards to get as much, as I can down.*

*(John, interview 1: lines 602-604)*

Initially he is hesitant in conveying his thoughts regarding how MND has progressed for him physically. This hesitance suggests that John is aligning, or composing, his thoughts regarding disease progression, to which he states that he is '*lucky*'. This suggests that his ability to create a digital legacy is somewhat attributable to an external locus of control due to the disease not currently affecting his speech and vocal abilities.

In contrast, for Tommy, the realisation that the disease had begun to affect his speech was the catalyst to begin recording his digital legacy.

*I looked into it but it's something you think 'ah I'll do next week, I'll do next week'. And I really noticed the change in my voice and I thought I'd start cracking on.*

*(Tommy: lines 73- 75)*

Tommy repeats the internal dialogue of '*I'll do [it] next week*', which emphasises his procrastination until he '*noticed the change in his voice*'. He then mentions that following the realisation that his vocal ability was diminishing, he decided to '*start cracking on*'. This infers a sense of a 'race' in recording his digital legacy before progression of the disease affects his vocal capabilities. Such a concept was later reinforced by Willow, an MND nurse (Chapter 8, page 227).

Manifestations of the disease causing physical decline were also noted by Alice as a motivator to create her legacy:

*Well what I've tried to do with MMMM [step-daughter], or what I'm hoping to do, 'cus my hands are getting really bad now so I need to get a move on, which I am, I'm trying to do lots.*

*(Alice: lines 269-271)*

Similar to Tommy, Alice discusses a pressure of time with a 'need to get a move on' to create her legacy whilst she is still physically able. This was something which was also described in later interviews (Chapter 8, page 226). Alice also highlights how basic physical movements such as use of her hands has declined as a result of the disease. This not only causes immediate practical problems with creating her legacy, but the hesitation in her final sentence also suggests concerns for the disease progression to overtake her legacy creation.

The underlying concept of time was similarly mentioned by John in his follow-up interview. In contrast, however, he discussed how he required a break from recording his digital legacy and reflected upon his struggle to regain motivation to begin recording again.

*[Beginning to record his legacy again] probably the break, the fact that my mobility is a bit less than before which reminds you that, you know, this bloody disease is continually progressing*

*(John, interview 2: lines 161-163)*

The use of ‘fact’ regarding his mobility exemplifies concrete and indisputable evidence for progression of the disease. As highlighted during the interviews with healthcare professionals (Chapter 8, page 224), John mentions that the physical symptoms act as reminders of the MND diagnosis and heighten awareness of inevitable death. He also emphasises the concept of time through an awareness that ‘*this bloody disease is continually progressing*’, suggesting his physical decline to be constant and incessant which has reduced his motivation to record his digital legacy. As such, a strong connection is inferred between progression of time resulting in advancement of the disease and reduced physical abilities.

#### 6.1.2- Conveyance of identity and past experiences

The motivation to create a digital legacy was also linked to a drive in plwMND wanting to convey specific past experiences to children in their family throughout their digital legacy. This is exemplified during the interview with Charlie who had previously mentioned that he used to be a quiz master in his local pub prior to his MND diagnosis.

*Wife: [...] Charlie did his last ever quiz on New Year’s Day, this year, and they had a bit of a presentation at the end, and the room was just full, it was brilliant. But they got all that on this video as well*

*Charlie: I did a speech, again*

*Int: have you got that video?*

*Wife: Yeah, it’s on a CD*

*Charlie: so, my kids can see that as well*

*Wife: yeah, so we’re going to keep that too*

*Charlie: you know, my grandkids*

*(Lines 472-483)*

Charlie's quick interjection regarding his delivery of a speech suggests feelings of pride. Building on this further, Charlie was receiving ventilator support for all but half-an-hour each day. This means that delivering his speech would have required significant physical effort which he was willing to expend in return for the opportunity to perform what, seemingly, would be his last speech, thus temporarily reasserting his identity. Interestingly, Charlie also mentions how the video of this speech could be seen by his 'kids', before later correcting to '*my grandkids*'. This is significant as he did not have any grandchildren at the time of the interview. He is therefore thinking ahead about his grandparent identity and role for children who are yet to be born. As such, the recording of this speech will be a way to convey himself and his personality to his future grandchildren. Consequently, Charlie was motivated to create his digital legacy because he '*just wanted to make sure they knew who [he] was and it's a personal message to them*' (line 220).

Similarly, this conveyance of past experiences shaping personal identity and character was evident in John's explanation of his digital legacy for his son.

*Because I wanted to put a record down. At one point I did a timeline of, a mini timeline of my life and where I had been and what I done and, you know, it was almost like a, 'and then after University I went to Africa and I did this, and did that'. Because I wanted him to know what I, you know, what I had done.*

*(John, interview 1: lines 105-109)*

In contrast to Charlie who discussed the documentation and recording of one specific event which exemplified his character and identity, John wanted to



document a number of milestone events through creating a timeline which would provide *'almost like a little book about, you know, DVD book about Daddy'* (interview 1- line 131). Both extracts from participants acknowledge that specific events and experiences have been crucial in shaping their identity. Consequently, it is deemed important to record such events in the digital legacy as a way to inform their respective children in the future about their lives. This was similarly identified as an important feature of the digital legacy within a later interview with Rita, a child bereavement researcher (Chapter 8, page 229). Yet, John also discussed the importance of including events and memories surrounding challenging times he had faced throughout his life.

*John: I want to be as, up front as possible, I mean without going into too graphic detail, but I had a very difficult time at school.*

*Int: Yeah*

*John: And suffered child abuse, suffered bullying so there's a lot of very difficult stuff in there that I want him to know about. So, because I just think, it's, it's relevant to what has formed me basically. So, in that sense I wanted to include, I do, I want it to include everything that hasn't always been very easy, to talk about that sort of stuff.*

*(Interview 1: lines 401-412)*

The hesitation and fragmentation of sentences in this extract exemplifies a process of aligning his thoughts whilst drawing upon emotive memories. Arguably, these hesitations are a result of cognitive overload due to the emotional evocation caused by considering these memories. Yet, after some hesitation, John provides his justification for including such challenging details. He uses the word *'basically'*, suggesting a phenomenological process of reduction as to why he fundamentally decided to include such difficult

memories for his son to watch in the digital legacy in the future. Consequently, such details are *'relevant to what has formed [him]'*, suggesting the digital legacy is not only intended to convey memories, but also to provide an element of justification or rationalisation for his personality and character. Interpreting this further, the digital legacy is a forward-thinking resource to be used by his son in the future to provide guidance and contribute to his development. Yet, it is also backwards-thinking through providing John with a way to document the various autobiographical details which, in turn, have shaped him. As such, creating his digital legacy has provided John with a cathartic opportunity *'to include everything that hasn't always been very easy, to talk about'*. This was similarly reinforced in a later interview with Mark, a hospice chaplain (Chapter 8, page 217). It is therefore clear that whilst there are a number of hoped-for benefits for his son in using the digital legacy in the future, there are also potential mutual benefits for the plwMND in creating the legacy and reflecting upon their own past and history.

The concept of identity conveyance and documentation of past experiences was also reinforced by Alice. In contrast, however, Alice wished to inform her son of how her identity developed through discussing her childhood and respective hobbies and interests.

*Alice: And also doing about me, you know, things from years ago. Things like RaRa skirts, Wham, Adam Ant, all the cartoons we used to watch*

*Int: Oh yeah?*

*Alice: So, you know, just things that he can look at and think. 'cus I didn't know that much about my Gran and when they were younger*

*(Lines 202-206)*

Alice mentions her Gran and perceived lack of knowledge regarding her younger years. Ironically, this past experience of not having biographical information about her grandparents, and crucially, a way to hear her their voices when they had died, actually motivated Alice to create a resource for her own children.

*[...] and for me, there's been times when, I mean I loved my grandparents and everything, and I would have loved to probably hear their voices*

*(Alice: lines 185-186)*

Alice emphasises that '*there's been times*' she has wanted a way to hear her grandparents' voices and wished she had a digital legacy which featured them speaking. In the previous quote, however, Alice also discusses that a digital resource such as this, would also provide her with historical information about her grandparents. Alice was therefore inspired to create a digital legacy for her son and step-daughter through consideration of her own personal experience and the digital legacy that she did not have when her grandparents died. She has evidently reflected upon what she would have found valuable from having a legacy during bereavement. This has subsequently inspired and motivated her to create a resource for her children which she herself did not have.

Lastly, motivation to create a digital legacy based upon past experience was also prominent in the interview with Charlie and his wife who had recently lost their daughter.

*Charlie: So, we haven't got any videos of, well we have got videos of VVVV, our daughter. But they weren't, sort of, final videos because you don't think of it when you're 22, that you're going to die*

*Int: no, you don't*

*Wife: what we did come across, she'd made little, like people do on phones now, [...] they'd video themselves, you know. And we found all these recordings on her laptop, and it was [tearful], just hearing her laughing*

*Charlie: Yeah [tearful], sorry, it's very difficult to talk about*

*(Lines 233-238)*

It is evident from this extract that the use of a digital legacy can be suggested to evoke strong emotions when viewing or hearing a recording of a deceased loved one. Poignantly, the videos consisting of their daughter's digital legacy, were not created with the intention to form a '*final*' legacy, in the same sense as Charlie's, as her death was not anticipated. Arguably, there is an alternative sentimental value for bereaved people watching the videos when there is an awareness that they have been recorded with the intention of being '*final videos*'. This idea was also reinforced by Becky, a bereaved young person (Chapter 7, page 201) and Willow, an MND nurse (Chapter 8, page 230). Regardless of this, the legacy held significant value to Charlie and his wife due to the captured sound of '*just hearing her laughing*'. This suggests that Charlie had first-hand experience of how valuable a digital legacy can be for bereaved people, which subsequently inspired him to create his own for future grandchildren.

## 6.2 - Purpose and hoped for use of a digital legacy

The second superordinate theme which was noted throughout the interviews was regarding the purpose of the individual's digital legacy and how they hoped that it would be used in the future.

### 6.2.1 - Parenting and guiding

Whilst it is clear that the types of digital legacy which plwMND recorded were varied, a common underlying hope or desire was that the digital legacy would provide an alternative method to continue parenting, or guide the young person following the plwMND's death.

*I still want that kind of input in [son's] life. I want him to know me, but also, I want him to, you know, to have morals, and good family values. That's the thing for me.*

*(Alice: lines 188-189)*

Whilst Alice does not immediately specify or define what '*that kind of input*' represents for her, she later states these as morals and family values. Arguably, these beliefs are individualistic and not ubiquitously shared across different families. This means that children will adopt family specific '*morals, and good family values*' through their parents and family. Interpretation of Alice's extract suggests that her legacy is therefore an alternative way to provide her son and step-daughter with morals and values which are desired by bereaved young people after the person has died (Chapter 7, page 195). She also states '*that's the thing for me*', suggesting this to be the overarching purpose and aim of her unique digital legacy.

In a similar vein, John discussed that the purpose of his digital legacy was to provide a point of reference for his son to consult in the future.

*There are things that I'm not going to be around for. You know, when, God the awful father-son talks. That you think, 'God, do I leave a few of those?' that he could just go to if he needs them? Because, that's what he's going to want, he's going to want to be able to go and talk to somebody, about, everything. About, you know, 'oh, I've got my first girlfriend', or, first sexual experience, whatever [...] those are the sort of things that you know, normally, Father's, would end up having chats with their son's, about, whether it's bullying or whatever the subject is.*

*(John, interview 1: lines 426-435)*

John provides practical examples of when he feels his digital legacy will be beneficial for his son and lists these with ease. This suggests a type of affective forecasting whereby John is attempting to predict when and how the digital legacy will be used by his son. There is subsequently a dual-process whereby John gains benefit from knowing that he will still be involved in his son's life, albeit in a digital form. This concept was similarly addressed in interviews with healthcare professionals and specialists (Chapter 8, page 232). Additionally, John's son will benefit from having a digital resource and bank of information to access which provides advice and guidance created by his father.

*You know, in the way that it's, it's there for him on a DVD almost laid out 'oh look, click on that video for, Daddy's answer to that question'.*

*(John, interview 1: lines 117-119)*

Of poignancy in this extract is how John estimates and predicts his son's thought process in using the digital legacy in the future. He indicates a hope

that his son will access the legacy through a process of generating questions and actively seeking ‘*Daddy’s answer to that question*’. Interestingly, John uses language which is commonly associated with relatively young children through use of the word ‘*Daddy*’. This contradicts with many of the topics John mentioned in the previous extract such as relationship advice and sexual guidance. Interpreting this further, John is faced with a challenge in wanting to create an encompassing digital legacy which will provide his son with appropriate guidance, well into his adolescent years. However, John seemingly struggles to predict the thought process of his adolescent son accessing the digital legacy. John therefore attempts to predict his son’s thought process, yet bases this on his current developmental stage. Consequently, there is a conflict between wanting to provide age appropriate material for his maturing son, but problematically, John is unsure how to best communicate this. It is therefore necessary to consider the young person’s developmental understanding of the content recorded within the digital legacy, a challenge for plwMND which was commented upon by Rita, a child bereavement researcher (Chapter 8, page 236).

Tommy also reinforced the idea of his digital legacy acting as a point of reference for his children to use once he had died.

*I mean they may think, what a load of garbage. You know what, I’d probably be happy with that as long as they’ve got their own minds, questioning, and evaluating everything. But if I can give them a baseline, if I can help anywhere, that’d be good.*

*(Tommy: lines 371-374)*

Of pertinence in this extract is Tommy's notion that his digital legacy will provide 'a *baseline*' which his children can later utilise to form their own ideas and concepts. This was similarly described during the interviews with bereaved young people (Chapter 7, page 185). As such, Tommy's legacy and the contents of the recordings are intended to develop key skills around '*questioning, and evaluating everything*'. Similar to John, the digital legacy created by Tommy aims to foster these skills through digital means, thus acting as a parental substitute as a result of his physical absence caused by MND and his inevitable death.

In contrast, the purpose of Charlie's digital legacy was to influence the lives of future children in his family by simply introducing himself. Akin to the perceptions provided during the interviews with healthcare professionals (Chapter 8, pages 213-215), this ensures that he will not be forgotten after his death.

*Yeah so that's all the videos were for really, to introduce myself to my, future family, my nephew's kids and my son's kids. People that I'll never meet, you know.*

*(Charlie: lines 391-393)*

Whilst Charlie created his digital legacy to be watched by his future grandchildren and his nephew's children, there was seemingly an awareness that his son and nephew would also view it.

*And, just to say that I think they've turned out to be good guys, and listen to what they have to say as you grow up 'cus I think they'll do the same for you, and make you into decent guys, that can achieve in life, and, you know, to say to work hard, at school, and you'll be a decent person.*

*(Charlie: lines 44-48)*



Evidently Charlie is providing advice and moral guidance through suggestion of *'listen to what they have to say as you grow up'*. Additionally, he offers encouragement for their futures and stipulates the areas which he perceives to be of importance to *'be a decent person'*. Seemingly, Charlie has also acknowledged that his grandchildren and great niece or nephew, will view the digital legacy in the company of their parents- Charlie's son and nephew. Therefore, the purpose of the digital legacy is not only to provide moral advice to his future grandchildren or grand-niece/nephew, but also to convey his pride and adoration for his son and nephew in their role of fatherhood.

#### 6.2.2 - Alternative purposes of the digital legacy

Whilst the most common purpose of a digital legacy for plwMND was to continue parenting and provide moral guidance to children in the family, participants also identified additional objectives of their legacy. John discussed how he recorded a number of videos for his son to generate a type of 'digital diary'.

*It's more literally like a diary of, sort of, things that have been going on, me watching how he's developing, progressing. Or maybe things that have happened in the house, or it can be anything. I mean at times feels probably quite mundane but, it's, it's kind of, also, a running progression that he can see, changes in me I guess?*

*(John, interview 2: lines 8-11)*

As stated by John, the purpose of this type of digital legacy was partly to provide *'a running progression'* by documenting his physical deterioration

throughout the videos. There could be a number of reasons for creating this type of video diary which contradicts later perceptions regarding a digital legacy capturing undesirable disease related characteristics (Chapter 8, page 219). Arguably, the primary reason for this is to ensure that his son can watch these videos in the future and become aware that John was not always in a paralysed state, thus emphasising his gradual physical decline. Furthermore, there is a sense of juxtaposition whereby John is reflecting upon his son's *increasing* development and progression whilst he is recording his legacy. In contrast, his son will watch the videos in the future and potentially reflect upon John's *decreasing* abilities as his physical condition declines due to disease progression.

Lastly, Charlie highlighted that an additional purpose of his digital legacy was to provide humour.

*Charlie: I have a Wallace outfit to be honest. And I've got a Gromit dog, so I use that to sort of, talk to my grandkids.*

*Int: talking through the dog?*

*Charlie: well no, I just say, as if I'm Gromit talking to them, sorry Wallace, with Gromit on my lap.*

*Wife: [laugh] oh dear!*

*Charlie: just to make it funny, you know, so they'll relate to that, but they'll have seen the videos probably when they're little*

*(Lines 33-40)*

### 6.2.3 - Hoped for use of the digital legacy

Throughout the interviews there was a common discussion and exploration of how plwMND hoped their digital legacy would be used by the children in the future. Something which was later described by Petra, a MND nurse (Chapter 8, page 220), was that the legacy would be utilised for specific milestone events in the child's life that the plwMND would be absent for.

*[...] those [videos] are kind of more like specific things for, birthdays or events in the future where you can leave a message for a very specific, sort of moment in his life whether it's, I dunno, I mean it's starting to get into weird territory when you're sort of thinking 'okay, I'll leave a message for, when he gets married, or, when it's a specific birthday or when he graduates, you know. So you're, you know, you're leaving a little message for certain bits, moments in his life where I'm not going to be there, that I can still leave him something.*

*(John, interview 2: lines 39-44)*

To provide some contextual information, John created a number of different types of digital legacy for his son using various online services and applications. In this extract, he describes videos for future events as '*those*', suggesting them to be distinct, with a separate purpose from the other recordings he has made. John then highlights some examples of the milestone events when this aspect of his digital legacy will hopefully be used by his son. Yet, he also mentions that '*it's starting to get into weird territory*' which emphasises some concern or reluctance in having to forward plan the specific events for which he is to record videos. John has arguably spent time predicting the various milestone events which his son will likely experience. However, in doing so, John is forced to omit himself from these projections

and acknowledge his imminent death. This was similarly highlighted as a key issue for plwMND in creating a digital legacy during later interviews with Petra and Willow, two MND nurses (Chapter 8, page 220).

The use of the legacy at specific milestone events in the child's life was also discussed by Alice.

*Alice: I'm just saying, you know, I want you to always support each other. So, I'm putting in little things like that*

*Int: for the future?*

*Alice: yeah, or if they go on holiday, first holiday. Yeah, it's exciting but, you know, watch your drinks and, make sure you look after your mates, just silly things like that. Things I'd probably say anyway*

*(Lines 540-545)*

Similar to John, Alice had projected herself into the future to ascertain the type of advice and guidance that she would have provided if she was still physically present. She states that the content is what she would '*probably say anyway*'. This suggests an accuracy to her legacy in documenting and recounting guidance. She predicts what she would '*probably say*' if she was still living at the time of the milestone event. This contrasts with John who described how he found it challenging to imagine his son as an adolescent. As such, John found it hard to predict or forecast the type of information that his son may be seeking from watching the digital legacy. This difference of experience between Alice and John may be a result of their children's age when the digital legacy was being recorded. It could be suggested that Alice may have found

it less challenging to record her digital legacy, as her children were older than John's son. Consequently, this additional time Alice has spent with her children, along with them being more developmentally advanced, may have afforded her with a better understanding of the information they may seek as they grow and mature, and how it should be optimally delivered. Fundamentally, however, this highlights a key challenge for plwMND in planning digital legacy content, something which was similarly commented upon during interviews with healthcare professionals and specialists (Chapter 8, page 222).

Charlie also talked about milestone events, albeit in a different context. He suggested that his grandchildren were to be of a certain age before they are shown his digital legacy and infers a hope that it will be repeatedly watched again in the future:

*Charlie: I said to [son] wait until they're about 5 or 6 before you do it*

*Int: yeah?*

*Charlie: and then they can appreciate it, they'll probably look at it again later on as they grow up*

*(Lines 222-225)*

The concept of when and how the digital legacy would be used by children, also stimulated thoughts around the event of death and subsequent child bereavement.

*And, as I say, it's a big unknown. I have no idea how, he is going to cope, with, grief and the loss of a father. I've no idea and it may be that [wife's name] has to, get some element of child therapy for him. I have no idea, he may not need any at all, but again, that may lead to somebody saying 'oh this would be a good moment to use this'.*

*(John, interview 1: lines 471-475)*

In this extract, John provides an overwhelming sense of it being 'a *big unknown*'. This is applicable to both his son's use of the digital legacy, but additionally, the 'unknown' of how his son will experience the forthcoming bereavement. John suggests a possibility of his son needing '*some element of child therapy*' following his death in which the digital legacy may provide some therapeutic use and benefit. Yet, as suggested in a later interview with Jess, a child bereavement specialist, the use of the digital legacy may need to be tailored in accordance with the young person's individual preferences (Chapter 8, pages 238-239). Crucially, however, while John has created videos in response to a number of anticipated events in his son's life, ultimately, he is unable to predict how his son will cope with the forthcoming grief. With this in mind, John has created and recorded his digital legacy in-line with his best predictions of what his son may require in the future. In the follow-up interview, John mentioned the anticipated use of the digital legacy in relation to the content being discussed.

*John: And in some senses, even if I don't answer a specific question, just the fact those videos, are there, that maybe covering something related to it that he wants an answer to, is going to be a comfort. 'Cus I'm sure there's going to be things that I don't answer*

*Int: yeah?*

*John: that there's moments when, 'ah this is when I wish dad was here, this is when I wish you know, he would have go, I would have like to have known what his answer to this would be'*

*(Interview 2: lines 260-266)*

John recognises that it is not possible to record videos in response to every eventuality his son may refer to the digital legacy for. Whilst he has previously projected himself into the future to predict what his son may need, or want from the digital legacy, in this extract it is clear that John has also predicted a scenario whereby the legacy does not provide this intended goal. Of further interest is John's exploration of related videos potentially being able to provide answers to his son's questions and offer comfort. This links to the principles of hermeneutics whereby an answer could be guessed or assumed by his son to a question that John has not explicitly answered within his digital legacy through watching '*something related*'. This idea of the digital legacy being able to indirectly inform the child was also reiterated by Tommy:

*[Regarding his perception of the digital legacy] my value is they can understand me and my thought process, what I've done in life and they've always got a record to check on.*

*(Tommy: lines 366-367)*

Tommy has identified two uses of his digital legacy by his children which is supported by accounts provided by bereaved young people (Chapter 7, pages 193-194). Initially Tommy states that the legacy will ensure his children '*can understand me and my thought process*', thus reiterating the hermeneutic potential of a digital legacy. Whilst this is more *implicitly* provided by Tommy's legacy, information regarding his memories and achievements in life are *explicitly* conveyed through the legacy content and delivery.

Similarly, John also acknowledged that capturing and providing an accessible recording of his voice is of importance and will be valuable for his son.

*So, I kind of know it's important, but at times, I have to remind myself that 'okay, he's going to really love listening to you, when he hasn't got you around'.*

*(John, interview 1: lines 593-595)*

Interestingly, a key feature of this quote is the internal dialogue which John provides. This suggests that it is something he has previously thought about and reiterates as a justification for why he should create his digital legacy. It also emphasises that John has once again projected himself to a future whereby he is absent due to the disease and death. He has then empathised with his future bereaved son in an attempt to understand that his father's voice will provide him with comfort during a clearly challenging time following his death. This was similarly addressed as an important feature of the digital legacy during the interviews with bereaved young people (Chapter 7, pages 188-192), and healthcare professionals (Chapter 8, pages 227-231).

### **6.3 - Challenges in creating a digital legacy**

It was evident throughout the interviews that plwMND faced a number of challenges in creating their digital legacy. These challenges are linked to the actual process of recording the legacy and fall into one of two ordinate themes, *planning and preparation to create the legacy*, or, *challenges throughout the recording process*.



### 6.3.1 - Planning and preparation

One of the commonly reported challenges in creating a digital legacy for plwMND, was regarding the planning and preparation of content to record. These challenges were perceived on a number of levels and were similarly reiterated during interviews with Rita (child bereavement researcher) and Pam (child attachment researcher) (Chapter 8, pages 223-224). As evidenced by Tommy, difficulties were faced in deciding what to include in the legacy, and how to optimally record it.

*And to try and get it as clear as possible to the kids, so it's got meaning to them. Um, that's really quite hard to do- I found anyway. I'm not the most articulate of people. So yeah, I'd think about it, write it down, go over it in my mind what I want to say and even try and practice it so I'm not stumbling so much.*

*(Tommy: lines 93-96)*

Tommy suggests that the process of recording the videos comprising his digital legacy involved an iterative process of planning and rehearsing prior to recording each video. Of pertinence is his goal to ensure clarity 'so *it's got meaning to them*'. There is also an inference that Tommy possesses limited confidence regarding his ability to articulate. Consequently, he developed a coping strategy to reduce a sense of feeling overwhelmed whilst recording his videos. Tommy mentions that he would write down the salient points before engaging in a phase of reflection to ensure the appropriateness and inclusivity of each video.

*I'd practice on my iPhone 'cus you can record on that. So maybe record something on there, see what it sounded like, whether it made sense or not.*

*(Tommy: lines 221-223)*

He additionally states that practising the delivery of the message was an important strategy to ‘*reduce stumbling*’ and enhance the likelihood of recording a natural and free-flowing digital legacy, as intended. As such, there was an active process of planning and reflecting for Tommy prior to recording his digital legacy. This interestingly contradicts with his idea of wanting to create a ‘natural’ feeling video which would feature his idiosyncrasies, something which bereaved young people suggested that they would prefer (Becky, Chapter 7, page 198).

In contrast, Charlie elaborated on his process of recording his legacy to be more spontaneous.

*Int: so how did you decide what to put in the videos then?*

*Charlie: I just did it off the cuff*

*Int: did you?*

*Charlie: just went straight off the top of my head. I’m quite good at that though. I’d sort of figured out in my head what I was going to say*

*(Lines 214-218)*

Unlike Tommy, Charlie alludes to a more impromptu recording of his legacy which did not involve prior note taking and rehearsing. This difference is arguably due perceived skills and abilities in articulation and public speaking which consequently resonates with theories on self-fulfilling prophecy. Whilst Charlie perceives himself to be skilled in this domain from his success as a pub quiz-master and lead singer of a band, Tommy has developed a coping strategy involving careful planning and preparation of what he will say in order to compensate for his perceived limitations.

John also faced challenges in the planning of his digital legacy due to a sense of artificiality in responding to unprompted questions.

*And you're having to, think about it more as well. You know, you're having to really think about your answer, a lot more carefully, whereas in real life, you would, you'd probably answer- you know, it would just come out very quickly, whatever comes to your head straightaway [...] life as we know, has a lot of distractions, and in a way this little thing even though it's, it can be quite clinical in a way it's done but you are having to sit and think about what you want to say, and probably give a much more in-depth answer than you would if you were doing it, face-to-face*

*(John, interview 2: lines 488-491)*

This implies that careful planning and consideration of video responses increases pressure and concern for the plwMND which requires them to '*really think about your answer*'. This is arguably due to the fundamental difference between a 'normal' conversation in the real world which may evolve and change when revisited, and the static nature of a digital legacy which is fixed and will remain unchanged. Consequently, the challenge of planning the digital legacy for plwMND is multifaceted and was discussed in detail during the interviews with healthcare professionals, specialists and experts (Chapter 8, page 224). The content must not only be accessible with the language used, but also be in-depth as unlike in everyday conversations, the fixed nature of a recording means natural conversational progression does not occur meaning clarification of certain details is not possible. Consequently, the content of the digital legacy must be carefully considered as to how and what will optimally support the child in the future.

John further suggests that a key aspect of the challenge in planning the digital legacy is regarding the accessibility of the videos and the language he uses.

*And so part of me is speaking, you know, talking in a way that I'm thinking he's listening as a grown-up boy. And then other times I completely forget about that and I'm talking to him as if he's, four, which he is. So, it is quite hard, sometimes to know what sort of tone, to leave messages in because you don't really know which of the two people, you're leaving messages for. My little boy now, you know? And I sort of, sometimes I'm talking to it like it's today and I'm leaving a message for him today*

*(John, interview 1: lines 82-89)*

Of pertinence in this extract is John's challenge in not '*really know[ing] which of the two people [he's] leaving messages for*'. This infers that whilst his son will physically be the same person regardless of the age he is when watching the legacy, his understanding of the content will evidently grow, change and evolve. Therefore, the challenge for John, is ensuring that the legacy is compatible with whatever age his son is when he uses the resource in the future.

*I always think, for some reason I think about those films when they watch, when people are going into space and they're leaving. They're leaving messages for people that are going to finally arrive with them, you know, in however many minutes or hours down the line- and you're basically, having to kind of, talk to somebody, you know, as personally as you can, but it does feel, a bit odd just not actually talking to that person.*

*(John, interview 1: lines 439-449)*

John states that he 'always' thinks about this challenge of planning appropriate content for his digital legacy. This is further evidenced by his development of an analogy to aid description and provide an accessible explanation of the

difficulties he faces during the process of recording his legacy. He adds that part of the challenge lies in talking to someone ‘*as personally as you can*’, when in reality, he will not *personally* know his son when he, John, has died. This is further exacerbated through acknowledging that his son’s personality will undoubtedly grow and develop as he matures, meaning John has no way of accurately knowing how his digital legacy will be received, understood and interpreted by his son in the future. Clearly the following analogy resonates highly with him and feels it accurately portrays his challenge as he similarly repeated in the second interview:

*You do feel like one of these sort of sci-fi characters on a spaceship sending a message off that’s only going to arrive on earth, X you know, X number of years later*

*(John, interview 2: lines 226-228)*

Arguably, this knowledge of how to communicate with adolescent children would evolve over time in normal parent-child relationships. A parent would implicitly modify how they speak and communicate with their child as dictated by their developmental understanding, idiosyncrasies, and, reaction to the topic being discussed. Yet, the static and one-sided nature of a digital legacy means that John will be unable to gauge his son’s reaction to delicate subjects and tailor the conversation accordingly. Furthermore, the fixed nature of a video will undoubtedly result in a number of questions generated by his son which will remain unanswered.

### 6.3.2 - The recording process

Similar to planning and preparing the content for the digital legacy, the actual process of recording each of the videos induced a plethora of unique challenges. Most notably was the emotional consequence that plwMND individually experienced during the process of recording. Tommy described how this influenced the way he delivered and recorded the videos for his digital legacy.

*Yeah and then getting it out, without the emotion, so yeah. And then struggling, when I get nervous or emotional my voice struggles even more so getting it out clearly, is something you want to do. So I've re-recorded quite a bit of it.*

*(Tommy: lines 81-83)*

Evidently, the process of recording his digital legacy evoked strong emotional reactions which Tommy felt were noticeable in his voice and made delivery a struggle. It was therefore important for him to ensure that his legacy did not possess such emotionality, which resulted in him reporting that he '*re-recorded quite a bit of it*'. This need to eliminate or reduce emotional content can be traced back to his central aim of the digital legacy- '*I didn't want to leave any negativity as a legacy for my family and kids*' (line 104). Poignantly, Tommy's experience of the process being emotionally demanding was similarly described during later interviews with healthcare professionals, specialists and experts (Chapter 8, pages 221-224). Tommy would therefore repeat the process of creating videos, thus elongating the period of emotionality, in order to achieve the goal of '*no negativity*' for his digital legacy. This contrasts heavily with the approach discussed earlier by Charlie who described how he

recorded his digital legacy '*off the cuff*' and '*straight from the top of [his] head*' (lines 214-218). This suggests that whilst Tommy had an underlying aim of recording videos with '*no negativity*', Charlie instead was striving to convey his spontaneity and identity as a performer.

In a similar vein, John also discussed how the process of reflecting on imminent death, through creating his legacy evoked emotion in a less physical, more psychological way.

*There is a conflict [...] between trying to kind of stay in the moment and not think too far ahead. And then inevitably you do videos, for the future, it takes you out of, you know, it is like a bit of a slap in the face each time [...] 'this is why you're doing it'. And it is inevitably emotional, talking about things that you wish you were there for to talk to him face-to-face about.*

*(John, interview 2: lines 197-204)*

John suggests that there is an internal process of conflict when creating the digital legacy '*between trying to kind of stay in the moment and not think too far ahead*'. This is John implying a resistance in thinking too far ahead to the future where he is no longer present, thus being challenged with a reminder of his forthcoming death (discussed further in Chapter 8, page 222). John therefore acknowledges that he will not be physically present in his son's future, instead, his aim is to have input to his son's life through digital means via the digital legacy. He suggests that this arduous psychological process of accepting his death and creating the digital resource, is likened to '*a slap in the face each time*', suggesting it to be a painful process for him.

Alice also reflected on the internal conflict that creating a legacy induces and noted the importance of balancing the time spent thinking about MND and her inevitable death.

*We talked about this this morning [to husband], I said about, it was a saying someone had said, that thinking about death or facing death is a little bit like looking at the sun, it's too powerful, it's too hot, and you can only look for a little bit and you have to turn away. And that summed it up for me to be honest, because it is. Yeah it is powerful, and yeah, I have to live with that every day, but I have to live as well. So it's kind of, you touch on it but you need to turn away.*

*(Alice: lines 563-571)*

Interestingly, Alice uses the analogy of '*looking at the sun*' to be similar to that of thinking and reflecting upon her illness and imminent death. This is pertinent, as like the sun, she has no control over the painful disease progression and premature death, perceiving it to be '*too powerful*'. Regardless of this, the psychological '*need to turn away*' was physically actioned and achieved through periods of not engaging with the legacy project. Tommy stated that his digital legacy '*took about three or four months 'cus it can be quite emotional*' (line 78) meaning he gradually recorded his legacy throughout an elongated period to ensure regular breaks. This reduced the likelihood of becoming overwhelmed which was similarly described as a key challenge during the interviews with healthcare professionals (Chapter 8, page 221). In contrast, John mentioned that he '*was really blitzing at one stage, almost like doing a couple of videos a day*' (interview 2: line 210). He later outlined that since this initial *blitzing*, he had given himself a break from recording the videos for a variety of reasons which induced difficulties in revisiting the project.



*John: so, and having left it a long time, I know I'm going back into doing it, it seems to be more of a bit of an emotional jump to get back into doing it because it reminds me, you know, in a way, 'oh, I know why I'm doing it', but also, the kind of sadness element of it is, it seems to be more there at the moment um. Don't know why*

*Int: is that because of the break do you think or is that because of?*

*John: probably the break. The fact that I've you know, my mobility is a bit less than before which reminds you that, you know that, this bloody disease you know, is continually progressing*

*(Interview 2: lines 156-163)*

This raises questions around the optimal time frame in which a digital legacy should be recorded for plwMND, an issue similarly discussed in the interviews with healthcare professionals (Chapter 8, pages 224-226). Whilst Tommy may have initially taken a longer time to create his videos, John implies a sense of burn-out before completing his legacy. It is also clear that John's symptoms of MND and physical decline have also negatively impacted upon his motivation to revisit his legacy project and cause additional logistical concerns with him needing assistance.

*It's getting harder for me to use that computer. Not impossible, but I kind of need someone to help give me the keyboard and the mouse and then I can sort of get onto it on my own. But, I'm more conscious when I've got somebody in the house, you know. I obviously don't want someone, sitting behind me when I'm leaving a message*

*(John, interview 2: lines 59-62)*

He explains that use of technology and the necessary equipment is 'getting harder' due to his physical decline. This means that John is required to seek support from other people, yet is understandably reluctant to discuss and record personal messages to his son when other people are present. He is therefore faced with a conflict between needing other people there to help him

with the equipment, but not wanting them in-situ during his recording. Consequently, there is an optimal period of time prior to significant disease progression in which plwMND should create a digital legacy.

*Tommy: Yeah, 'cus I noticed when I started [digital legacy], and when I finished, the decline in my voice. So, it's just got to be done early.*

*Int: As soon as?*

*Tommy: As soon as you read about it*

*(Lines 59-62)*

Tommy implies that there is a sense of a 'race' between being psychologically able to record the digital legacy, and being physically able to record it before significant disease progression has occurred. This concept of a limited window of time to create the digital legacy was similarly discussed in the interviews with healthcare professionals, specialists and experts (Chapter 8, page 225). Yet, Tommy and Charlie also attributed the ability to begin recording their digital legacy to have reached a level of acceptance regarding their illness and imminent death.

*I've been fortunate, that I've got everything ready. And also, I think you have to accept, the future, and be proactive, 'cus I know a few people that won't even touch this kind of stuff because they won't accept their condition or what's going to happen in their future, and then it's too late*

*(Tommy: lines 54-57)*

*When you've got all this time, coming up to your funeral, 'cus you know it's going to be soon, you tend to do a lot of thought about it, you know? When you're diagnosed it's denial and all that, and then, you come to accept it, you lie here thinking for hours on end. Then you accept that you're going to die, so then you put things in place, so certain songs you want playing at your funeral [...] then a video for your grandkids.*

*(Charlie: lines 129-134)*

## 6.4- Intrinsic benefits for plwMND creating a digital legacy

Throughout this chapter I have discussed a number of the perceived benefits that plwMND experience in creating a digital legacy for a child in their family. Many of these benefits, however, were connected to the perception of the digital legacy's value for their children. Yet it was also evident from the data that the plwMND, themselves, also experienced benefits through creating their digital legacy. These benefits fell in to one of two themes; *the digital legacy as a project*, and *reflecting upon memories*.

### 6.4.1 - The digital legacy as a project

A key intrinsic benefit that creating a digital legacy provided for plwMND, was the ability to channel time and efforts towards the legacy.

*I knew I was going to have a lot of time on my hands, and in a way, I saw it as a project. You know, something to really focus on [...] having a terminal illness is obviously a bummer, but I see it as very positive to have, to be doing this, to be leaving for him*

*(John, interview 1: lines 186-191)*

John describes how creating his digital legacy provided him with a project which offered '*something to really focus on*', resonating to that described later by Rose, a palliative care nurse (Chapter 8, page 218). This suggests that his focus, attention and efforts which were once crucial for his journalism career, suddenly became obsolete as the disease progressed and his physical condition worsened. Yet, recording his digital legacy provided a way to

channel these attributes in accordance with the disease progression and physical deficits. John reinforces this by outlining that '*whilst having a terminal illness is obviously a bummer*', he recognises a positivity in being able to create and bequeath his digital legacy to his son. He later extended this perception during the second interview by highlighting that:

*Most people who get ill, you know, there is a feeling of helplessness, and not feeling that they've got any purpose at all, and, it does give you a sense of purpose to leave something, that you wouldn't ordinarily have left, you know?*

*(John, interview 2: lines 480-482)*

This suggests that the process of creating the digital legacy provided John with a sense of purpose, a point also highlighted during the interviews with healthcare professionals (Chapter 8, pages 217-219). John also states that having a terminal illness instils '*a feeling of helplessness*'. Yet, in this extract, he infers that leaving a legacy reduces this sense of helplessness and provides him with a sense of control as he is able to create a resource for his son despite his declining physical capabilities. Arguably, the process of creating a digital legacy has reinforced John's internal locus of control through providing him with a sense of influence and control over his illness and reduced physical abilities. Consequently, whilst John may not be able to parent his son in the physical way he did prior to onset of the disease, he is able to parent in an alternative, digital form. This also promotes a sense of autonomy for John as he is able to record his digital legacy in accordance with his reduced physical capabilities. This was similarly reinforced by Alice:

*I think that with MND, that's the thing 'cus it's always one step ahead. [...] but the things I can do myself is personal to me and it's, a way of me, I dunno whether it's acceptance or I'm grieving, I dunno, but it's a positive thing for me.*

*(Alice: lines 277-280)*

In this extract, Alice implies a sense of race between succumbing to her physical decline and through mention of MND and how *'it's always one step ahead'*. This implies that the disease is continually progressing, whilst Alice is forced to constantly adjust to new symptomatology. More importantly, however, Alice emphasises that whilst her physical condition worsens, her legacy is one of the few things she can now do herself, thus providing a sense of control and independence. This was similarly reinforced in a later interview with Rose, a palliative care nurse (Chapter 8, page 218). Furthermore, Alice suggests that the process has offered therapeutic benefits through encouraging acceptance of her illness, and grieving the loss of her future.

#### 6.4.2 - Reflecting upon memories

An additional intrinsic benefit in creating a digital legacy for plwMND was regarding the process of reflecting upon memories and past achievements.

This was discussed in the interview with Tommy:

*Int: And how was the process of some of the earlier stuff when you were talking about your childhood and your- he's got a smile, is that a good smile?*

*Tommy: Yeah, it's a good smile! Remembering it in, what's the word I'm looking for, I had a great childhood, so trying to get that over [...] Yeah, um, just brought back good memories and now my kids have the same kind of memories.*

*(Lines 181-190)*

Of pertinence is Tommy's physical reaction to smile when considering his reflection upon childhood memories. This evidences his enjoyment in revisiting the memories and including them within his digital legacy, a point also made by Kirsty, a palliative care consultant (Chapter 8, page 217). Tommy also states that his '*kids have the same kind of memories*' suggesting that during his process of reflecting and recording his digital legacy, he has compared his childhood with that of his children's and noted common parallels. Tommy outlines that he '*had a great childhood*' and due to his acknowledgement of parallels between his and the children's formative years, Tommy gains comfort in knowing that his children will experience similar childhoods to his as they grow and develop.

Tommy was also instilled with a sense of pride and achievement through reflecting upon his life during the process of creating his digital legacy.

*I left school with no qualifications and I went into a factory job because I didn't have any confidence at school and one day I thought, 'I'm better than this'. So, I went to college, and I moved up in life. I think, bettered myself and I'm grateful for other people but [in] my experience, you can achieve if you put the effort in.*

*(Tommy: lines 334-337)*

Tommy would have initially begun reflecting upon his life and memories being stimulated by creating his digital legacy. Yet, interpretation of this extract suggests that whilst revisiting his memories to record his legacy, he has additionally reflected upon significant lifetime achievements. This was

described by Rose, a palliative care nurse, as a process of 'remapping' (Chapter 8, page 218). Tommy describes the transition that he made from leaving school with no qualifications and low confidence, '*to moving up in life*' and '*bettering himself*'. Consequently, the process of recording his digital legacy not only endorses the revisiting of memories, but also promotes a sense of pride and realisation in regards to significant lifetime achievements in the plwMND's life.

## **6.5 - Summary**

Within this chapter I have described the findings generated from the interviews conducted with four plwMND. These findings have been categorised into four superordinate themes; *i) motivation for creating a digital legacy, ii) purpose and hoped use of a digital legacy, iii) challenges in creating a digital legacy, and, iv) intrinsic benefits for plwMND creating a digital legacy*. Themes were developed from a consensus across all participants.

The next chapter will discuss the findings generated from the interviews with the bereaved young people regarding the use of a digital legacy.

## **Chapter 7- Findings: the experiences of bereaved young people using a video legacy**

“When someone you love becomes a memory, the memory becomes a treasure.”

Unknown

In this chapter I will present findings from the interviews conducted with bereaved young people regarding their experiences of using a video legacy.

As in the previous findings chapter (6), I will begin by providing an overview of the sample before offering a short biographic narrative for each participant.

### **7.0 - Sample and data collection**

Due to the broad recruitment strategy and the use of various dissemination approaches adopted to publicise the study, it was not possible to definitively record how many bereaved young people were supplied with information packs. However, two bereaved young people were sent study information through Facebook after initiating contact and expressing interest in the study. Similarly, two bereaved young people were emailed documentation in response to adverts placed in charity newsletters. Four hard copies of information packs were disseminated to people in attendance at MND Association branch meetings.



Despite employing numerous methods of recruitment as described in Chapter 5, it was not possible to recruit bereaved young people who had used a purposefully created digital legacy. It was anticipated that recruitment of participants for this phase of the study would be challenging due to the requirement of young people to revisit highly emotional memories associated with their bereavement. Furthermore, there would be a limited population of young people bereaved by MND who met the inclusion criteria by having access to a digital legacy. This was anticipated due to technology only becoming accessible and affordable to the majority of people during recent years. Consequently, there would be a limited population of bereaved young people who had access to a purely digital legacy created by a plwMND.

As a result of this, three bereaved young people were interviewed about their experiences of using a video legacy which featured their fathers who had died from MND, in accordance with the definition of a digital legacy provided by Bassett (2015) in Chapter 2. These legacies were therefore not purposefully created and prepared by their fathers prior to death. Consequently, the interviews with bereaved young people focussed upon their experiences of using a video legacy recorded on a cassette which was identified following the death of the plwMND. In total, three young people were recruited and interviewed from the South West and North West of England. The interviews ranged from 27 to 37 minutes with the mean duration of 33 minutes. Similar to

the interviews with plwMND, it was anticipated that these interviews would be short in duration as a result of the emotionally evocative topic being discussed. The participants were therefore encouraged to engage in a period of reflection prior to the interview about their experiences of using the video legacy. This reflection ensured that participants had already considered a range of experiences of using the video legacy which could be retrieved during the interview. All participants were interviewed face-to-face in accordance with their preferences, and given pseudonyms to promote anonymity. Becky requested to be interviewed in a local cafe, whereas individual interviews were conducted with Isabelle and Sophie in an office at the university. As with the findings previously presented for plwMND, a brief synopsis of biographical information is offered for each participant along with a summary of details in Table 6 (page 181).

### Becky

Becky's father was diagnosed with MND in 1997 when she was 10 years old and he died in 2010. She was born and raised in the South West of England and was one of four children. There was an age gap of two years between Becky and her older brother, two years between herself and younger brother, and lastly, seven years between Becky and her younger sister. At the time of the interview in May 2016, Becky was 19 years old and studying English Literature at University with a deep passion for writing in her spare time. She

had learnt about the study after attending her local MND Association branch meeting where I had presented my study and requested contact from willing participants. Becky's video legacy had been created by her mother following the death of her father to provide Becky with a 'Dad fix' when required. The videos were therefore a compilation of various recordings of special family events such as birthdays, christenings, weddings and Christmases. Her mother had compiled a selection of these videos onto one cassette with Becky's father being the central focus.

#### Isabelle and Sophie

Isabelle and Sophie were sisters recruited from an MND Care Centre in the North West of England. Isabelle was one year older than Sophie, and Sophie was one year older than their younger brother. Originally from Italy, their father was diagnosed with MND in 1996 when Isabelle was three, and Sophie was two. He died in 2000 after four years of living with the disease. Following their father's death, the three siblings and their mother moved back to the North West of England to be closer to maternal family. During a return trip to visit family in Italy during 2015, the three children were shown a video cassette which had been transferred to DVD and featured their father during a wedding, thus constituting their video legacy.

*Table 6- A summary of participant and video legacy characteristics*

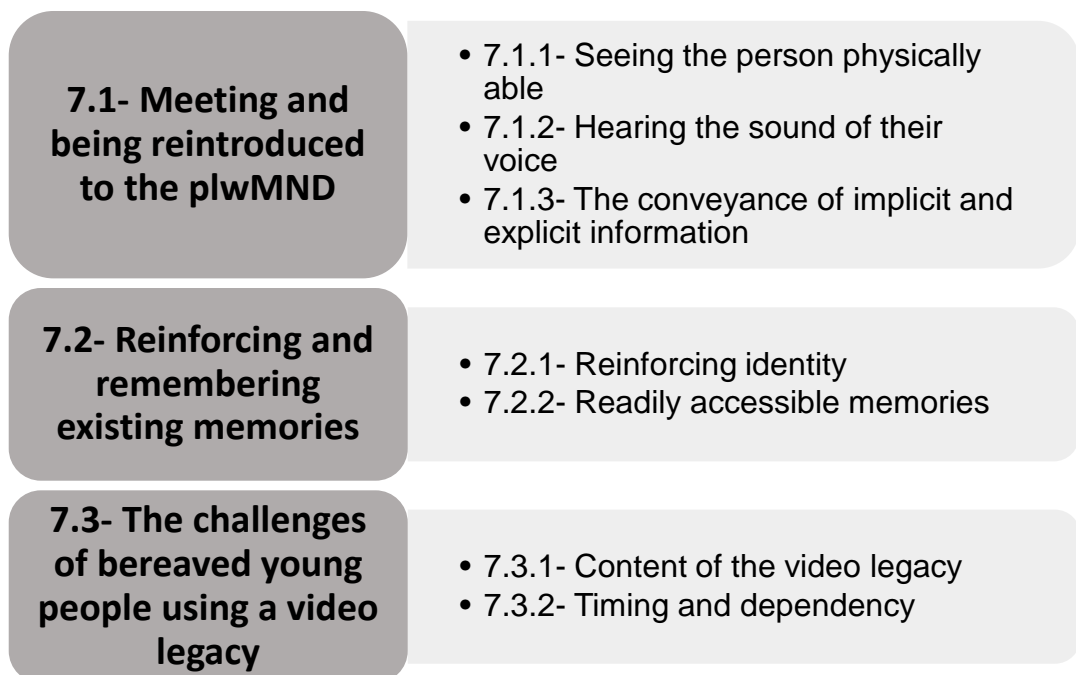
Pseudonym	Type of video legacy	Age when parent died	Siblings	Participant location	Method of recruitment	Date of interview	Age at interview	Duration of interview
Becky	A compilation of videos recorded during special family events	13	<ul style="list-style-type: none"> <li>• Older brother</li> <li>• Younger Sister</li> </ul>	South West	MND Association Branch meeting	May 2016	22	36 mins
Isabelle	One short video of a family wedding	7	<ul style="list-style-type: none"> <li>• Younger sister (Sophie)</li> <li>• Younger brother</li> </ul>	North West	NHS MND Care Centre	June 2017	24	37 mins
Sophie		6	<ul style="list-style-type: none"> <li>• Older sister (Isabelle)</li> <li>• Younger brother</li> </ul>	North West	NHS MND Care Centre	July 2017	23	27 mins

### 7.0.1- Analysis

As with the interviews conducted with plwMND, verbatim transcription was carried out by myself prior to replication of the data analysis process, including a process of auditing by my supervisory team. Similar to the previous findings chapter, I will present anonymised interview extracts from the bereaved young people alongside my analytical interpretations.

In total, three superordinate themes and seven subsidiary ordinate themes were developed in accordance with Smith's quality evaluation guide for IPA research (Smith, 2011, page 132). Themes were therefore prevalent in all participant cases and summarised below in Figure 14 to highlight the relationship between superordinate and subsidiary themes.

*Figure 14- A summary of the superordinate and ordinate themes generated from the interviews with bereaved young people.*



## 7.1 - Meeting and being reintroduced to the plwMND

A key theme identified throughout the interviews was that watching the video legacy provided the young person with a sense of 'meeting' or being 'reintroduced' to their deceased parent again. In contrast to remembering their parent through recalling information that the young person already knew, 'meeting' or being 'reintroduced' suggests that they are provided with new and unknown information about their parent.

### 7.1.1 - Seeing the person physically able

It was described by the bereaved young people that watching the video legacy provided a way to see their parent almost living a different life, prior to onset of the disease.

*So it was nice, but, it was just weird because I've never seen him as a person that could do all those things, I just remember him not being able to do all those things. I just remember him not being able to do the things, and it's nice to know that he wasn't always ill*

*(Isabelle: lines 67-69)*

In this extract, Isabelle describes how watching the video legacy enabled her to see her father in a new light. She outlines that she could '*just remember him not being able to do the things*', yet watching the video legacy provided her with a sense of proof '*that he wasn't always ill*'. Isabelle also infers conflicting feelings when watching the video legacy through describing that whilst '*it was nice*', it did not stimulate and reinforce her existing memories of her father which were centred upon him being ill. This was similarly reinforced as a key

benefit for bereaved young people by Rose, a palliative care nurse (Chapter 8, page 230). Isabelle built upon this further in the interview by suggesting that it was:

*[...] nice to see him in that video because he is happy and he's not what I remember him like. He's having fun and was able to do stuff, for himself.*

*(Isabelle: lines 115-116)*

Poignantly, Isabelle suggests that the video provides a way to see her father *'having fun and was able to do stuff'*. As such, Isabelle gains comfort and happiness from seeing an alternative, previous version of her able-bodied father which heavily contrasts to her existing memories of him being ill. She explains that the fundamental reason she gains comfort from accessing the video legacy exemplifies that *'he is happy and he's not what I remember him like'*. Arguably then, the video legacy may provide a way for Isabelle to modify her existing memories of her father being ill and alter her knowledge that he was not always unhappy. This was a concept similarly described throughout the interviews with healthcare professionals, specialists and experts (Chapter 8, page 230). Of further pertinence is that Isabelle was only seven years old when her father died. This means she is unlikely to have an abundance of memories of him before this age due to the limitations associated with typical child development. Accessing and watching the video legacy therefore provides a retrospective way to create pre-disease memories of her father which will predate her own recollections that are focussed upon the disease and related symptoms.

This idea was also discussed by Sophie, Isabelle's younger sister, who similarly described that watching the video legacy provides her with a way to:

*Think 'yeah, he was happy before'. 'Cus I don't remember him smiling, at all. 'Cus obviously you don't really remember things when you're a baby [...] I think my earliest memories are of when he was ill. Which is a shame.*

*(Sophie: lines 109-112)*

Interestingly, Sophie also highlights a lack of memories of her father due to being in her infancy when he developed symptoms. In contrast to Isabelle, Sophie explicitly describes that a fundamental aspect of the video for her, was the ability to see her father smiling. Whilst this highly specific and physical action is unique to Sophie's experience of watching the video legacy, it reinforces Isabelle's notion of seeing their father happy before becoming paralysed. This evidence of their father's happiness is clearly an important feature of the video legacy, and as suggested by a number of healthcare professionals, will assist Isabelle and Sophie to develop a biographical narrative of their father (Chapter 8, pages 230-231). Furthermore, the perceived value of the video for the sisters, is the implicit conveyance of their father once being physically able, and not always being 'unhappy' as a consequence of the disease.

Sophie went on to describe that the video legacy provided additional proof of physical abilities beyond recognising that her father could once smile.



*I know that he was really active. He used to love running, he had a lot of medals for running and stuff. But with the way that I saw him, I could never even imagine that he could even walk, in a sense. 'Cus I was just so used to seeing him in bed 24/7, that it'd just be weird.*

*(Sophie: lines 123-126)*

Sophie describes an awareness that her father used to be 'really active', which heavily conflicts with her memories of 'seeing him in bed 24/7'. As such, imagining him being physically active and running, is almost an impossibility as it is so opposing to her memories of him. Watching the video legacy therefore provides a type of evidence to challenge her existing memories and perceptions that he was not always paralysed and bed bound. In accordance with experiential learning theories (Kolb, 1984), witnessing her father walking in the video legacy could be used as a foundational memory which Sophie can later build upon when imagining the stories about his physically active lifestyle before onset of the disease. This resonates with the aim and purpose of Tommy's legacy who hoped that his digital legacy would provide a baseline of knowledge for his children regarding himself and his life (Chapter 6, page 153). This was similarly reinforced by Sophie's older sister, Isabelle.

*Yeah, it was so strange, it was like seeing a new person, like it wasn't even him, because I can't remember him like that. It was hard, but it was nice. It's something that I keep now, when I think of him I also think of that video as well so it's not all 'oh he was ill and he couldn't do anything'.*

*(Isabelle: lines 125-128)*

Isabelle emphasises that seeing her father within the video legacy being able to walk and unaffected by disease symptoms, *'was like seeing a new person'*. She goes on to describe that this feeling was attributable to such a strong juxtaposition between her memories of her father when he was ill, and the recording of him in the video. Interestingly, Isabelle notes that *'when I think of him I also think of that video as well'*, thus reinforcing this idea of experiential learning theories as watching the video creates a new memory of their father before the illness and paralysis.

#### 7.1.2 - Hearing the sound of their voice

In a similar vein, Sophie also described how the video not only provided a valuable way to visually 'meet' a physically able version of her father, but also hear how he sounded through listening to his recorded voice.

*The voice was, I wouldn't even picture that voice, for him, and that's a weird thing to say. But when you can't really remember what your dad sounds like and then you hear a voice and putting the two together. That again makes you feel dead happy and kind of like, 'ah, that's who my dad is'. Yeah, there's no other way to describe it. It's just a really nice feeling like 'ah'.*

*(Sophie: lines 154-157)*

Sophie describes a sense of surprise in hearing her father's voice. She states that she *'wouldn't even picture that voice, for him'*, suggesting that she had no recollection or idea of how his voice once sounded. This resonates with later comments from Rita, a child bereavement researcher, who highlighted that the sound of a person's voice is often quickly forgotten after they have died (Chapter 8, page 228). Interestingly, Sophie also mentions an active process

of not being able to *'really remember what your dad sounds like'*, inferring that she still seeks to recall how he sounded. Sophie suggests that hearing the recorded sound of his voice enables a valuable process of *'putting the two together'*. This is arguably referring to the ability to apply the auditory sound of his voice recorded in the video legacy, to the various stories, knowledge and memories that Sophie possesses of her father. She can retain the sound of his voice and apply it to a host of alternative contexts and memories. Interpreting this further, her father had already lost the ability to speak when Sophie was in her infancy, meaning she had no memories of how he sounded. As such, accessing the video legacy for the first time will also have been the first time she had heard her father's spoken voice. She highlights that this created a positive feeling of being *'dead happy and kind of like, 'ah, that's who my dad is'*. This sense of comfort in hearing his voice was built upon further in the interview.

*I wanted to hear his voice for so long, and I think I used to just try so hard just to think about a memory where, like, I even thought about him saying my name or anything like that. But I just couldn't think of anything. So finally, when I heard his voice, even though he wasn't saying anything in particular, he was just laughing and maybe calling one of our names or something. It was just nice, it just felt more real than just looking at photograph.*

*(Sophie: lines 175-179)*

In this extract, Sophie describes a long-standing and fundamental drive to be able to hear her father's voice. She mentions how she *'used to just try so hard just to think about a memory'* which contained the sound of his voice. Clearly,

due to her young age when her father became ill, she lacked any memories of how his voice once sounded to draw upon. Interestingly, Sophie outlines that within the video legacy *'he wasn't saying anything in particular, he was just laughing and maybe calling one of our names or something. It was just nice'*. As described in the previous chapter, with reference to Tommy (Chapter 6, page 161), this suggests that the explicit content of what is being said in the recordings is not always of fundamental importance. Instead, Sophie gained a sense of comfort and pleasure from the implicit ability of simply hearing the sound and tone of her father's voice.

Isabelle later expanded upon the pertinence of hearing her father's voice in the video legacy. She began to describe her perceived value of being able to hear him after I discussed my own personal experience.

*Int: so I've just got this answer-phone message, but I try to listen to that and think about, 'a normal dad sort of thing would be to say, you know, just get on with it and do this, this and this'. And you try to use that recording with your imagination*

*Isabelle: yeah, I totally get that*

*Int: but it's, it's just really hard, isn't it?*

*Isabelle: you don't have all the pieces to the puzzle*

*Int: that's exactly it! [laugh] Oh, well done!*

*Isabelle: but it's better than none, isn't it?*

*Int: it's better than no pieces*

*Isabelle: it is nice. And now you know what he sounds like and what he might have said, you're closer to that than not at all*

*(Lines 185-195)*

Isabelle suggests that hearing her father's voice provides additional '*pieces to the puzzle*', thus resonating with later perceptions from healthcare professionals (Chapter 8, pages 227-231). Isabelle therefore compares her lack of knowledge about her father, including the way he sounded, to that of a puzzle suggesting it to be confusing and difficult to understand. Interestingly, she infers that hearing his voice provides additional pieces to the puzzle which then begin to complete the full picture of who her father was, and what he was like.

In contrast to Isabelle and Sophie who gained a sense of comfort from hearing their father's voice, according to Becky, her sister experienced less desirable emotions and feelings to accessing the video legacy.

*My younger sister, yeah. She's jealous, like, such a ridiculous amount. Well not ridiculous but an extreme amount of sadness in them. She hears this voice in the video and goes 'but I don't know who that is'. Whereas I look at it so fondly and go 'ah' I love hearing that again. And I suddenly have moments, and it's such an amazing thing [...] how sound triggers things and triggers memories and you know, the same as smells, and as soon as you hear something and it takes you back to the time. And I walk past someone now who's got a really strong welsh accent and I instantly go 'ohh'*

*(Becky: lines 288-294)*

Of poignancy in this extract is the difference between Becky and her sister's reactions; with Becky gaining comfort and enjoyment from using the legacy, whilst her sister is faced with '*an extreme amount of sadness*'. Becky perceives her sister to be jealous of her for possessing memories of their father's voice due to being older when he became ill. Experiencing a negative reaction to hearing the plwMND's voice was similarly described by Jess, a child

bereavement therapist (Chapter 8, page 240). Becky continued to postulate the origins of her sister's reaction and jealousy after watching the video legacy.

*Becky: [...] and my sister who can't, because she doesn't have a memory of him. She has memories that we've given her, which I think is really hard to acknowledge is that if she watches, a video. Like my mum was fantastic and recorded the children growing up. So, she'll watch a video of my dad in it and will go 'oh no I remember that' and she doesn't, she remembers seeing the video or seeing a picture and having a story explained to her, but no-one in a million years would turn around and go 'well you don't remember it, do you?'*

*Int: She wants to remember remembering it?*

*Becky: She wants to remember remembering it, and that's the difference. She can't remember any of his voice was gone when she was four. And I don't know about you but my earliest memories are from about four onwards, five onwards. And even then, are a little bit hazy*

*(Lines 259-268)*

Interpretation of this extract suggests that the opposing reaction between Becky and her sister is largely associated with their different ages when their father died. Becky mentions her sister has '*memories that we've given her*', primarily due to her young age when their father died. She suggests that her sister does not have her own unique memories meaning she is reliant on stories from other family members and the video legacy. In contrast, Becky was older when her father lost his voice and later died, meaning she possesses memories which her sister does not. Arguably, the video legacy provides comfort to Becky as it reinforces her existing memories, as noted by a number of healthcare professionals (Chapter 8, pages 228-229). In contrast, Becky's sister experiences a sense of discomfort due to not having these baseline memories to nurture.

### 7.1.3 - The conveyance of implicit and explicit information

It was clear that using a video legacy to create new memories is not always a process that provides a sense of comfort and happiness to bereaved young people. Such challenges in using the video legacy were also evident during the interview with Isabelle.

*I felt like I learnt a lot from just watching, and he wasn't speaking to the camera, it was just him doing whatever, sitting down and like, it was a party so he was like just drinking or whatever. And I was in the video as well, and I could see him holding me and things like that, and it was just weird because I don't remember that. [Tearful] And I just kept looking at it and I thought 'that's what it was like, but I just don't remember it'.*

*(Isabelle: lines 62-67)*

In this extract, Isabelle initially describes a perceived benefit of watching the video legacy and learning about her father through the implicit information being conveyed. She outlines that whilst he explicitly '*wasn't speaking to the camera*', she could see him '*holding [her] and things like that*'. This implies that Isabelle felt like the parent-child relationship was being implicitly conveyed within the video legacy, thus evidencing the bond she once had with her father. Unsurprisingly, this induced an emotional reaction during the interview with Isabelle realising '*what it was like*'. This was also highlighted as a challenge for bereaved young people by Pam, a child attachment researcher, who suggested that the video may act as a reminder of the death and loss (Chapter 8, page 237). Yet Isabelle also infers that part of the emotional reaction is attributable to the fact that she does not '*remember it*'. As such, there is an element of frustration and sadness that she simply cannot remember the

relationship and bond that she once had with her father which is evidenced by the video. Interestingly, Sophie also commented upon her perception of the parent-child relationship with their father in the same video.

*Yeah, so it was nice to see. It's kind of like, in a sense, a person that I didn't know, just because I don't remember it happening in the flesh*

*(Sophie: lines 148-149)*

Similar to Isabelle, Sophie reiterates an inability to '*remember it happening in the flesh*'. Yet Sophie seemingly gains a sense of comfort from seeing how her father interacted with her, as evidenced by the video legacy. Poignantly, Sophie mentions that in the video, her father is '*in a sense, a person that [she] didn't know*', due to lacking memories of her formative years.

Sophie also described how the video legacy provided evidence of the parent-child relationship through the way in which her father physically interacted with her and her siblings.

*Sophie: it's just the way he was with us as well. You could tell that he was like squeezing us and throwing us in the air, not in a violent way [laugh]. Just playing around and stuff*

*Int: yeah, it's kind of like evidence, isn't it?*

*Sophie: yeah, that he did love you, obviously I know that he did, but I don't have memories of him playing with us, like, any other time. So just seeing that for the first time*

*(Lines 132-137)*

Interestingly, Sophie infers the video legacy provides a type of evidence which reinforces the idea that '*he did love*' her when he was alive, thus reinforcing a sense of continued connection described by the healthcare professionals



(Chapter 8, pages 232-234). Sophie also highlights a value in being able to witness how her father physically played with them as children by '*squeezing [them] and throwing [them] in the air*'. This suggests that whilst she 'obviously' knew that her father loved her, being able to visually see the physical relationship he had with them as children further strengthened and exemplified his parental love. Interpreting this further, the video legacy not only provides evidence of a loving parent-child relationship, but also creates substitutionary memories of this relationship which the bereaved young person can draw upon at a later point in time if required. Consequently, the implicit information contained in a video legacy may not only evoke an emotional reaction for bereaved young people, but can be recognised as being extremely important in conveying a wealth of meaning.

In contrast, Becky describes a belief that the inclusion of additional explicit information regarding her father's past and life before becoming ill would have been beneficial.

*Why not tell us the story about getting pissed around [town], naked?  
I just think that's great for my sister to know, actually, he was a  
human and he had a laugh before he died. He did live. He wasn't  
this person who was all buttered up, and stayed at home suddenly*

*(Becky: lines 531-534)*

Becky believes that the inclusion of information and stories about her father's past would have been beneficial for her sister. Seemingly, Becky is already aware of such stories yet perceives her sister to have an inaccurate representation of their father as '*this person who was all buttered up, and stayed at home suddenly*'. According to Becky, the inclusion of such stories through explicit delivery within a video legacy, would promote a sense of

knowing that '*he had a laugh before he died*' and that '*he did live*'. As suggested during the interviews with healthcare professionals, this would contribute towards developing a narrative of the plwMND's life (Chapter 8, page 231). Similar to Isabelle and Sophie, Becky perceives it to be important that her sister is aware that their father had a fun, happy and enjoyable life prior to becoming ill. As such, the video legacy becomes a type of resource which conveys information implicitly by evidencing the person's speech and physical function, but also explicitly through the content of what is being told.

## **7.2 - Reinforcing and remembering existing memories**

In contrast to the previous theme where bereaved young people suggested that a video legacy provided a way to create new memories of the person, this second theme is focussed upon reinforcing and stimulating existing memories.

### 7.2.1 - Reinforcing identity

Becky described gaining a sense of comfort from accessing her video legacy and re-establishing her familial identity.

*That's where I come from, that's who I am, it's not everyone else's views and opinions. Obviously you are influenced by people around you but, I needed [to] keep [a] strong idea that, that was my childhood*

*(Becky: lines 413-415)*

In this extract, Becky describes her justification and rationale for accessing her video legacy. She suggests that watching the videos provided her with a sense of knowledge and security regarding her familial origins. She outlines that whilst we '*are influenced by people around you*', she found comfort in using the video legacy to reinforce opinions and ideas originating from her childhood.

This infers that the video legacy may have the potential to act as a type of repository for core family morals and values which the young person can revisit through watching the videos. This resonates with the purpose and aim of Alice's legacy (Chapter 6, page 151). Becky further reinforced this idea through emphasising that:

*Going back to the videos was like a little slice of heaven because it was like 'that's my family, that's who I've been told what not to do by'*

*(Becky: lines 346-347)*

Interestingly, Becky outlines that accessing the video legacy provides a sense of comfort comparable to 'a little slice of heaven' by reinforcing her ideas and beliefs about her family portrayed in the videos. This further reinforces the idea of a video legacy conveying valuable implicit knowledge for a bereaved young person in the form of family values. This means that the actual content of the recording was less important for Becky and the reason for her using it was to provide her with a sense family identity and belonging.

In contrast to familial identity, Isabelle described that her use of the video legacy provided her with a way to become informed of her father's unique personality and identity.

*Isabelle: I think, yeah, just to see if you're anything like him or if you're a lot different from him. I don't know. It's all those questions that never really get answered. Obviously mum will tell you about him and all your family members will, but it's not the same as actually knowing the person*

*Int: yeah, or seeing it for yourself*

*Isabelle: yeah, I don't know, like, seeing a video or listening to a voice message, kind of brings you a little closer to that. It's comforting, isn't it?*

*(Lines 152-159)*

Poignant in this extract is the idea of self-comparison *‘to see if you’re anything like him or if you’re a lot different from him’*. Akin to Becky, it is seemingly important for Isabelle to learn and remember her origins. However, in contrast to Becky, Isabelle is focussed more upon the unique identity and personality of her deceased father. She suggests there to be a fundamental drive to answer *‘all those questions that never really get answered’*, thus resonating with the idea of young people having a ‘natural curiosity’ regarding people who have died (Rita, child bereavement researcher, Chapter 8, page 231). Interpreting this further, these *‘unanswered questions’* are suggestive of Isabelle wanting to better understand key aspects of her father, through a natural curiosity and drive to become more self-aware. She mentions that whilst *‘mum will tell you about him [...] it’s not the same as actually knowing the person’*. Consequently, the ability to see and hear her father within the video legacy, provides an opportunity to *‘get a little closer’* and be reminded of his idiosyncrasies, thus enabling Isabelle to learn of the characteristics and traits which she has inherited and shares with her father.

Becky further built on this concept of identity formation through reflecting upon her bereavement and use of the video legacy.

*He was lovely, an amazing man, very dedicated to his family, loved us dearly, and the one that everybody admired. But he wasn’t the easiest person to get along with, he was very stubborn in his views and very difficult. And I’d like to know about that. I hate that everyone was like ‘ah no, you know, he’s just this fantastic guy, he’s passed away so no one speak badly about him’*

*(Becky: lines 521-525)*

Interpretation of Becky’s quote suggests that bereaved young people may seek a holistic view of the plwMND, almost a ‘warts and all’ approach. She has

clearly reflected upon her memories of her father and acknowledged that he had his own idiosyncrasies, which formed his identity. Becky is therefore suggesting that she would have liked a holistic overview of her father which encompasses some of the imperfections which shaped him just as much as the widely recognised positive characteristics. This contradicts with Tommy's wish to create a well-polished and rehearsed video legacy (Chapter 6, page 163).

#### 7.2.2 - Readily accessible memories

Distinct from using the video legacy to create memories of a time they did not remember with their Dad (Section 7.1), it was also suggested that existing memories could be reinforced and stimulated with use of the video legacy. This was similarly described throughout the interviews with healthcare professionals, specialists and experts (Chapter 8, page 228-229). Isabelle described how the presence of the video legacy could provide a sense of comfort through acting as a type of evidence which would validate her existing memories.

*I was really young so I was only seven, so I really only remember my dad being ill and I have no memories of him not being ill and being able to walk. But I don't know if those memories are real or if I've just made them up. Because you think, you're so young, you might just think, they might be a dream or something- 'I had a dream and now I think it's a real memory'. So it's nice to have something that you know is, that's actually real, if that makes sense?*

*(Isabelle: Lines 39-43)*

Pertinent in this extract is that Isabelle suggests that she may have *'had a dream and now I think it's a real memory'*. Yet, whilst dreams are typically associated with fantasy or magical connotations, Isabelle has focussed on a more realistic image of her father *'not being ill and being able to walk'*. Interestingly, Sophie also mentions that whilst she has memories of her father, she is unsure whether *'those memories are real or if [she's] just made them up'*. Interpreting this further, the video legacy provides a way for Isabelle to reinforce her existing memories and validate memories of her father *'not being ill and being able to walk'*. She is therefore able to prove to herself that the imagery and memories she has in her mind were *'actually real'*. This in itself may be a source of great comfort for bereaved young people as: *'you know it's real and you know you've not made it up [laugh]. Yeah, it's nice to have something physical that just adds to whatever you've got in your mind (Isabelle, lines 53-54).*

Sophie similarly commented upon the benefit of the video legacy being readily accessible to stimulate existing memories.

*I think the positive would be obviously, seeing them speak, like the memories that you would usually forget. Little things, maybe their voice, just little things about them, obviously you'll be able to see them anytime you want*

*(Sophie: lines 209-211)*

Similar to a number of healthcare professionals (Chapter 8, pages 227-231), for Sophie, hearing the recorded sound of her father's voice is the fundamental stimulator for memories. She mentions that *'you would usually forget'* some

memories, specifically, how the person's voice sounded. She further reinforced this idea by mentioning that:

*It's been a long time since I saw that video so the voice has kind of gone again, but immediately after, I was thinking about it for weeks afterwards. Yeah, it gives you some sense of security I suppose.*

*(Sophie: lines 164-166)*

Akin to Rita (child bereavement researcher) and Petra (MND nurse) (Chapter 8, pages 228-229), Sophie infers that auditory memories of the person may possess more fragility than more visual memories and can be forgotten more easily. Consequently, the accessibility of a video legacy enables the young person to readily stimulate and reinforce both visual, and auditory, memories whenever required. Sophie highlights that this may provide 'some sense of security' in knowing that the person's voice can be heard again if the memory fades. Isabelle reinforced this idea through emphasising that: 'you could always re-listen to the message or re-watch the video, so it's kind of nice to have that memory that's not just in your head but you've physically got it' (lines 34-36). This was suggested during the interviews with healthcare professionals, specialists and experts, to provide the bereaved young person with a way to 'self-soothe' throughout their grief journey (Chapter 8, page 236).

This notion, that the recorded sound of the person's voice could stimulate memories for the bereaved young person, was also described by Becky.

*I suddenly have moments, and it's such an amazing thing that, you know, we spoke about the way it is, how sound triggers things and triggers memories and you know, the same as smells and as soon as you hear something and it takes you back to the time.*

*(Becky: lines 329-332)*

Becky highlights that hearing her father's voice provides a form of transcendence whereby she is taken '*back to the time*'. This arguably suggests that hearing her father's voice enables Becky to not only remember him, but also '*triggers*' a process of being able to relive the associated memories. Interestingly, this was similarly described by Alice and acted as her motivation to create her legacy (Chapter 6, page 149). Thus, a sense of comfort is provided by both hearing her father's voice, and mentally re-experiencing a connection and relationship with him once again.

### **7.3 - The challenges of bereaved young people using a video legacy**

Whilst it is clear that the participants perceived their video legacy to be valuable and provide a number of benefits, it was also evident that a number of challenges were encountered during accessing the videos.

#### 7.3.1 - Content of the video legacy

One of the challenges that the bereaved young people outlined regarding their video legacy was a dearth of content specifically recorded for them by their parent.

*I wish that he'd kind of done more, in the sense that he prepared for his illness and his death because if he'd come to terms with it maybe it would have been easier for us to have as children. I wish that he'd left something specific for us in his Will, so that we had something we could chat about, that was his, that was given to us personally.*

*(Becky: lines 307-310)*



Here, Becky suggests that receiving a purposefully created video legacy from her deceased father, would have supported her and her siblings by conveying his awareness and acceptance of the disease. Becky highlights that a purposefully created video legacy would be evidence that *'he'd come to terms with it'*, which in turn, may have made things easier for her. Poignantly, she also emphasises that part of the value and perceived benefit of purposeful video legacy, would be that it *'was given to us personally'*. This infers that the purposeful nature of creating and bequeathing the video legacy for the young person has comparable value to the actual content and the specific messages that have been recorded. This was a concept similarly addressed during the interviews with healthcare professionals, specialists and experts (Chapter 8, page 232).

Further to this, whilst Becky valued her compilation of videos recorded during special family events, it unfortunately did not contain explicit information about her father's life and beliefs, which she desires.

*We don't have him telling us what he had gotten up to or what he'd believe in everything, so you kind of have to make up your own assumptions of what he'd say and the advice he'd give*

*(Becky: lines 503-505)*

Becky explains that she does not have a video legacy with her dead father which explicitly told *'us what he had gotten up to or what he'd believe in everything'*. As such, there is a wish for the video legacy to contain more information to help develop a biographical narrative of the plwMND (Kacey, Chapter 8, page 230). Becky states that she makes her own *'assumptions of what he'd say and the advice he'd give'* based upon her existing knowledge of her father. Consequently, a video legacy that has been purposefully created

will suggestively provide an additional base of knowledge so that bereaved young people, like Becky, can develop their own assumptions regarding topics and issues which may not have been discussed explicitly in their legacies.

In contrast to this, Isabelle described that possessing a knowledge of the video legacy content would make viewing it again challenging.

*Isabelle: I definitely want to see it again, I've only seen it that one time. I think I'll probably be even more taken aback the second time because I know what's coming, and it's like, 'oh wow' [tearful], it's amazing*

*Int: yeah, you know what's on there so you know what to expect, which would kind of make it nicer but also harder as well?*

*Isabelle: yeah. And it kind of makes you feel like, not angry, but it's not fair [...] 'this is what it could have been like, but, we don't have that'. And it almost makes you more sad because you know what they were like, a little bit, like you can see them.*

*(Lines 159-167)*

It is clear from this extract that thinking about watching the video legacy again evokes a strong emotional reaction in Isabelle. She mentions that she will '*probably be even more taken aback the second time because I know what's coming*'. This suggests that there may be specific elements or sections of the video legacy which are more emotionally evocative than others. Isabelle also refers to a sense of anger before rephrasing to sadness due to recognising that the video legacy provides evidence of '*what they were like*'. Arguably then, a perceived challenge of the video legacy content, for Isabelle, is that it reinstates a sense of loss by highlighting '*what it could have been like, but, we don't have that*'. As also inferred by Pam, a child bereavement researcher (Chapter 8, page 240), the video legacy depicts an opposing version of what life and Isabelle's relationship may have been like with her father, if MND had not occurred.

### 7.3.2 - Timing and dependency

The time period in which a video legacy is used by a bereaved young person was also mentioned by Becky who reflected upon the period following her father's death.

*I watched them [videos] I think pretty soon after [death]. I think you have, I feel, like a six month period, where you are numb and you don't know what's happened to you*

*(Becky: lines 332-333)*

Becky's quote subsequently raises questions regarding the timing when bereaved young people use a video legacy. She emphasises a period of numbness whereby '*you don't know what's happened*'. This is evidently an important consideration related to the grieving process for the individual through ensuring that the death of the plwMND has been properly processed before watching and using the video legacy.

Similarly, Sophie also discussed the optimal timing in which she believed a young person should access a video legacy.

*I think maybe, you need time to not get over it as such, but kind of find peace with what's happened. And then once you're over the pain, I think it's beneficial to relive the memories. But I think maybe so soon after, you're kind of stuck in the bad place of just thinking about it*

*(Sophie: lines 218-221)*

Sophie emphasises the importance of '*time to not get over it as such, but kind of find peace with what's happened*'. This resonates with future

acknowledgements regarding the use of the digital legacy during an appropriate time within the young person's unique grief journey (Chapter 8, page 238). Sophie suggests that '*once you're over the pain*' and have begun to accept the loss, '*it's beneficial to relive the memories*' through use of the video legacy. Interestingly, Sophie suggests that watching the video legacy '*so soon after*' the death and early on in the young person's unique grief journey, could get them '*stuck in the bad place of just thinking about it*'. Sophie built upon this idea further and suggested that:

*Maybe you could get hung up on it? I think I probably would. Photographs are different, you look at them and get sad, but you can put them down. Whereas maybe something so visual as a video, I know I would probably replay it for weeks. If you're having a bad time, then you probably would, and I know that I would if I had it with me*

*(Sophie: lines 211-215)*

Interestingly, Sophie highlights a fundamental difference between photographs and videos where '*you look at them and get sad, but you can put them down*'. This highlights that bereaved young people react differently depending on the format of the resource which was similarly commented upon by Jess, a child bereavement therapist (Chapter 8, page 240). Sophie mentions that with '*something so visual as a video*', it might be hard for a bereaved young person to simply put it away when they get sad. She suggests that a young person may develop a type of dependency in accessing the videos whenever they are '*having a bad time*' which may induce a number of additional complications during their grief journey.

*I think sometimes too soon is maybe too painful. It will always be painful but I think later on, maybe if you needed comfort, I think that would be the way to go about it*

*(Sophie: lines 227-228)*

With this in mind, Sophie infers that the optimal period in which a bereaved young person accesses a video legacy is when they have progressed further in their unique journey. This ensures that watching the video legacy provides the young person with a sense of comfort when they require, instead of the potential evocation of upset and pain.

## **7.4 - Summary**

Within this chapter I have described the findings generated from the interviews conducted with three bereaved young people regarding their experiences of using a video legacy. These findings have been categorised into three superordinate themes; *i) meeting and being reintroduced to the plwMND, ii) reinforcing and remembering existing memories, and, iii) the challenges of bereaved young people using a video legacy.* Themes were developed from a consensus across all participants.

The next chapter will discuss the findings generated from the interviews with healthcare professionals, specialists and experts.

## Chapter 8 - Findings: the perceptions of healthcare professionals, specialists and experts regarding the use of digital legacies with people affected by MND

“Life is difficult. Not just for me or other ALS patients. Life is difficult for everyone. Finding ways to make life meaningful and purposeful and rewarding, doing the activities that you love and spending time with the people that you love - I think that's the meaning of this human experience.”

Steve Gleason (1977- )

In this chapter I present the findings generated from the interviews conducted with healthcare professionals, specialists and experts regarding their perceptions of digital legacies with people affected by MND. This section will begin with a brief overview of the sample characteristics before proceeding to discuss the findings which have been categorised in two master themes; *plwMND creating a digital legacy (Section 8.1)*, and, *young people using a digital legacy (Section 8.3)*.

### 8.0 - Sample and data collection

A maximum purposive sampling technique was adopted for this phase of the study which enabled the recruitment of 20 participants from across England (Saunders, 2012; Cresswell, 2013; Gray, 2014). In accordance with IPA principles, the shared perceptions of digital legacies contributed to homogeneity across the sample (Smith, Flowers and Larkin, 2009). Participants were therefore specifically recruited in order to provide

supplementary data and verify emerging themes from the interviews conducted with plwMND and bereaved young people. A summary of participant characteristics is provided below in Table 7. Views and perceptions were gained from three distinct groups of participants regarding their perspectives of digital legacies with people affected by MND. These smaller subgroups were dependent upon participant job role or specialism which is additionally outlined in Table 7.

The method of data collection was dependent upon participant preference. All participants were interviewed individually with exception of Jess and Kacey who opted to be interviewed together due to time constraints. Face-to-face interviews were conducted in the participant's place of work with the mean duration being approximately 21 minutes. In contrast, telephone interviews were shorter in duration with a mean of approximately 13 minutes. Whilst it is recognised that short interviews are somewhat uncommon for IPA research, it was also necessary to acknowledge that experience and knowledge of digital legacies would be a narrow and specific element of participants' clinical practice.

Table 7- A summary of participant characteristics.

Group	Pseudonym	Job Role	Context of Employment	Location	Method of Data Collection
MND	Jackie	MND nurse	NHS MND Care Centre	North West	Telephone
	Pearl	MND care advisor	Charity	North West	Telephone
	Petra	MND nurse	NHS MND Care Centre	North West	Telephone
	Willow	MND nurse	NHS MND Care Centre	North West	Telephone
	Roxy	MND nurse	NHS MND Care Centre	South	Telephone
Palliative care	Grace	Palliative care therapist	Palliative care charity	North West	Face-to-face
	Kim	Palliative care consultant	Hospice	North West	Telephone
	Mark	Chaplain	Hospice	North West	Face-to-face
	Ada	Chaplain	Hospice	South West	Face-to-face
	Harriet	Day centre staff	Hospice	South West	Face-to-face
	Kirsty	Palliative care consultant	Hospice	South West	Face to face
	Laura	Day centre staff	Hospice	South West	Face-to-face
	Rose	Palliative care nurse	Hospice	South West	Face-to-face
	Sue	Diversional therapist	Hospice	South West	Face-to-face
Child bereavement	Jess	Child bereavement therapist	Bereavement & loss charity	North West	Face-to-face
	Kacey	Child bereavement therapist	Bereavement & loss charity	North West	Face-to-face
	Pam	Child attachment researcher	Academic	North West	Face-to-face
	Billy	Social worker & researcher	Academic	Yorkshire & the Humber	Face-to-face
	Rita	Child bereavement researcher	Academic	Yorkshire & the Humber	Face-to-face
	Kelly	MND children & young people specialist	Charity	East Midlands	Telephone



### 8.0.1 - Analysis

As stated in the previous findings chapters (Chapters 6 and 7), all interviews were transcribed verbatim by myself prior to data analysis. In accordance with IPA principles, anonymised interview extracts are presented alongside detailed analytical interpretations of the data which provide the richest examples of the identified superordinate and ordinate themes (Smith, Flowers and Larkin, 2009). It was also necessary to draw upon guidance from Smith (2011) regarding the presentation of findings from larger sample sizes (Chapter 5, page 132). Accordingly, themes were deemed acceptable if prevalent in at least half of the total sample size ( $n=20$ ). A summary of prevalence has been provided at the beginning of each master theme to provide clarity (Table 8 and 9).

In total, four superordinate themes and nine subsidiary ordinate themes were developed. These are summarised below in Figure 15 to highlight the relationship between themes.

*Figure 15- A summary of the superordinate and ordinate themes generated from the interviews with healthcare professionals, specialists and experts.*



## 8.1 - plwMND creating a digital legacy

This master theme encompasses findings related to plwMND creating a digital legacy. This will consist of two superordinate themes; *Benefits and value for plwMND creating a digital legacy*, and, *challenges and barriers for plwMND creating a digital legacy*. Both of these themes include an additional four subsidiary ordinate themes which will be discussed in turn. In keeping with guidance provided by Smith (2011) in Chapter 5 (page 132), a summary of the distribution of themes across the sample is presented below in Table 8.

Table 8- A summary of theme prevalence.

	Superordinate theme	Ordinate theme	No. of participants	No. of references
plwMND	Benefits and value for plwMND creating a digital legacy	To not be forgotten	10	21
		Providing a sense of purpose and relief	13	33
	Challenges and barriers for plwMND creating a digital legacy	Psychological challenges and barriers to creating a digital legacy	16	50
		Practical challenges and barriers to creating a digital legacy	16	32

### 8.1.1 - Benefits and value for plwMND creating a digital legacy

A key theme identified throughout the interviews with healthcare professionals, specialists and experts, was that creating a digital legacy may provide a number of benefits for plwMND. Consequently, two ordinate themes were created; *'to not be forgotten'* and *'providing a sense of purpose and relief'*.

### 8.1.2 - To not be forgotten

It was suggested throughout the interviews that creating a digital legacy may provide a number of intrinsic benefits for plwMND. One such benefit was associated with reducing the likelihood of being forgotten after the plwMND has died.

*[...] patients might worry about not being remembered and I think particularly if they have young children. You know, as part of that existential worry or uncertainty that can come with going through the dying process and coming to terms with your mortality and the fact you're going to die. Some people are worried about being forgotten, or about really special memories that have been had.*

*(Kirsty, palliative care consultant: lines 41-45)*

Kirsty highlights that being forgotten provides an existential concern for plwMND, particularly if there are young children in the family. This is due to the fragility of memory for developing children meaning they may possess limited or no memories of the plwMND once they have died. Similarly, Jackie described how a young person's memory of the plwMND may be shaped by recollections of 'the final days' (Jackie, MND nurse: line 72). As such, memories of the plwMND being acutely ill due to significant disease progression, may overpower and distort any memories from before this period. Therefore, a digital legacy created before significant disease progression has occurred, ensures that '*they'll always be remembered how they were at that time and not in the final days*' (Jackie, MND Nurse: lines 71-72). Sue suggested that this provides something '*a bit like immortality [...] a sense that their life is going on*', albeit in a digital form (Sue, diversional therapist: line 257). This was further reinforced by Mark who described how a digital legacy

provides a way to create '*digitalised and personalised [...] and almost eternalised*' memories (Mark, hospice chaplain: line 346). Crucially, however, the '*immortalised*' identity of the plwMND stored within the digital legacy, will have been recorded in a timely manner prior to significant disease progression. As suggested by Jackie, they are consequently remembered by the young person from this '*eternalised*' image of more positive memories, instead of the potentially more recent ones created during the end of the plwMND's life. This interestingly contrasts with one of the purposes of John's digital legacy for his son which was to provide a '*running progression that he can see, changes in me, I guess?*' (John, Chapter 6, page 155). It therefore becomes clear that some plwMND may desire their digital legacy to include some elements of the disease progression.

This concept of eternalisation was further developed by Ada. She described how a digital legacy promotes a continued existence of a plwMND for bereaved young people. Ada described how particular aspects of the plwMND could be captured within a digital legacy.

*[A digital legacy] is also something that has the capacity to live on into the future. And it's a way of capturing a voice, a mood, even maybe a silent hug over the airwaves. So it's a third dimension of memory, of somebody once they have gone*

*(Ada, hospice chaplain: lines 4-6)*

The 'third dimension of memory' which Ada refers to describes the endurance of the plwMND's identity and memories within the young person, as transferred by the digital legacy. This links with Jackie and Mark's discussion around

immortality and eternalisation. From a slightly different perspective, Ada mentioned that a digital legacy can convey explicit features of the person through '*capturing a voice, a mood*', and likens this to a '*silent hug over the airwaves*' for the young person. Consequently, whilst Kirsty, Jackie and Mark describe the existential benefits for the plwMND in creating a digital legacy, Ada further highlights the potential benefits for young people who receive the recordings.

### 8.1.3 - Providing a sense of purpose and relief

An additional intrinsic benefit that creating a digital legacy may provide plwMND, was the opportunity to ruminate on the illness and their forthcoming death. Of pertinence was the idea of reflecting and remembering memories which may provide a sense of transcendence beyond the illness and related symptoms.

*I think some people really struggle more if they feel as though they're just waiting for the end and life hasn't got meaning anymore, and I think to be able to give it [life] some meaning [...] so you now spend your time, doing that, thinking about experiencing those memories. So thinking about how you can still do things for the family*

*(Kirsty, palliative care consultant: lines 146-149)*

This perception was similarly reinforced by Sue who described how reflecting and documenting memories can help plwMND to get '*in that space, [where] time sort of stands still, and you're able to go without an awareness of discomfort and anxiety*' (*Diversional Therapist, lines 57-58*). Sue went on to describe how the process of creating a digital legacy can 'side step' symptomatology because plwMND become '*engaged in something that they*

*enjoy, that they're doing something that they want to do, and they're enjoying that moment of creating it' (lines 113-115).* This was suggested to provide longer term benefits for plwMND through providing a sense of achievement and building self-confidence after engaging in the process of creating a digital legacy. This is evidenced by John's experience of creating his digital legacy and thriving upon having '*something to really focus on*' (Chapter 6, page 173). Rose further described how this may be bolstered due to the actual use of digital technologies to create the legacy. She outlined that using digital devices such as smartphones and tablets, enable plwMND '*to be able to sit there and record*' in harmony with their physical capabilities (*Rose, palliative care nurse: line 225*). As such, creating a digital legacy would be '*perfect for them*' and provide a sense of purpose through embarking on a project that they can carry out independently (*Rose, palliative care nurse: line 226*).

In addition to this, Rose reflected upon the immediate benefits for plwMND in creating a digital legacy. She had provided care to a plwMND in the past who had created a number of recordings for her two young children. Rose observed that the plwMND began to '*remap*' her negative perceptions of the illness, and became focused on the '*nice things*' achieved throughout her life.

*[...] it gave her the opportunity to focus on the nice things. And I've talked about that with our psychologist and she said it's actually called remapping. [...] So, you sort of rewrite your history really. And so for her, it was very beneficial because she learnt to stop focusing on the bad things and remember all the really nice things that happened in her life, and focus on those instead.*

*(Rose, palliative care nurse: lines 200-204)*

An alternative benefit, described by Mark, was that creating a digital legacy may provide a sense of cathartic relief for plwMND.

*[creating a digital legacy provides] an opportunity to say things that they may not have a way of expressing, a way of getting things off their chest. A way of, I suppose to use a traditional phrase, 'making peace'. I don't mean, you know, we were talking before about, it shouldn't be used for confessions to use the traditional word or anything like that, but, just the cathartic benefit of knowing you've been able to say the things that you wanted to say; to give you that back up if you're not able to say them*

*(Mark, hospice chaplain: lines 496-499)*

In contrast to Rose who suggests a digital legacy provides a way to 'remap' and resolve internal cognitions, Mark describes the value of creating the legacy to prompt outward expression. He suggests that the process of creating a digital legacy may prompt plwMND to '*get things off their chest*', which he associates to that of a traditional confession in certain faiths. As with Rose, Mark also outlines that this process of self-expression stimulated by creating the digital legacy, endorses an internal shift or sense of resolution through '*making peace*' and '*knowing you've been able to say the things that you wanted to say*' (Mark, hospice chaplain: line 498).

### 8.2.1 - Challenges and barriers for plwMND creating a digital legacy

The second superordinate theme which was noted throughout the interviews was regarding the various challenges and barriers that plwMND may face when creating a digital legacy. These primarily fall in to one of two ordinate themes; *psychological challenges and barriers*, and, *physical challenges and barriers*.



### 8.2.2 - Psychological challenges and barriers to creating a digital legacy

A number of psychological challenges were discussed during the interviews which were connected to various stages of disease progression. As described by Rose, the first psychological challenge is identifying an appropriate window of opportunity to create the digital legacy.

*It's got to be timely. You leave it too late, you can miss the boat. Or, if it's too early, they know it's something that they want to do but they don't feel quite ready yet.*

*(Rose, MND nurse: lines 171-173)*

Consequently, the challenge is making sure that plwMND are not only aware of 'the boat', but making sure that people can 'board it' when they are psychologically ready to do so, prior to disease progression meaning it has already departed. This resonates with comments provided earlier by John, Tommy and Alice who highlighted that an awareness of their disease progression motivated them to begin recording their digital legacies (Chapter 6, pages 143-144). Participants suggested that plwMND should be made aware of the possibility of creating a digital legacy early in the disease trajectory when physical capabilities remained intact. Grace, a palliative care therapist, suggested that this would '*just plant the seed and [they can] walk away from it and then come back to it*' (line 72). This interesting analogy infers that '*planting the seed*' shortly after diagnosis, ensures that the plwMND will still be physically able to create their legacy when this '*seed*' grows. However, sometimes this seed is planted too late meaning the plwMND's physical capabilities are significantly diminished which results in a lost opportunity.

*It's too late sometimes. And often some people will not think about it until it's too late and then they're not able to do it.*

*(Kim, palliative care consultant: lines 150-151)*

The importance of providing information in a timely manner was similarly reinforced by Pearl, an MND care advisor. She emphasised the need to *'inform[ing] people of the idea and let them consider it [...] as soon as possible'* (Pearl, MND care advisor: line 44). This would reduce the likelihood of plwMND getting *'to a point where it's much too late'* to create a digital legacy after later deciding that it is something they wished to pursue (Pearl, MND care advisor: line 47). There may also be a reluctance to record videos later in the disease trajectory due to the plwMND having *'worries of body image with how they look, how they sound'* (Kirsty, palliative care consultant: line 224). Some plwMND may therefore feel that the digital legacy inaccurately represents them, and instead, captures features and characteristics that have been dictated by the disease.

The realisation of time being limited for plwMND was also identified as a contributing factor to potentially becoming overwhelmed by the thought of creating a digital legacy. Roxy commented that plwMND often have *'a lot on their plate at once'* (MND nurse: line 59) and creating a digital legacy *'might just be that one extra thing that they can't get their head around'* (Willow, MND nurse: lines 77-78). Furthermore, some plwMND *'are changing so dramatically'* which means they do not *'have the space in their heads to sit and do this, although they want to'* (Roxy, MND nurse: line 60). This problem is further amplified as *'you don't start thinking about digital legacies until you're on a life shortening path'* (Willow, MND nurse: lines 78-79). With this in mind, creating a digital legacy may be better suited to people who have slower forms of the disease, or those who can begin the legacy soon after diagnosis. This could reduce the sense of feeling overwhelmed as a result of being in a *'race'* with progression of the disease, as described earlier by Tommy (Chapter 6, page 172).

It was also suggested that the process of creating a digital legacy would evoke some challenging thoughts and emotions for plwMND. Most notably, the process of wanting to provide a digital legacy for a young person would remind the plwMND that they would not be present in the future. This is clearly evidenced within John and Alice's experience of creating a digital legacy (Chapter 6, pages 170-171). As such, plwMND are frequently reminded of their imminent death and loss of future.

*I think lots of people talk about the future and 'I'm not going to be there for when my daughter gets married or has a baby or goes to school', certain life milestones. I think just thinking about those is really, really sad for the people with MND, and they know they're going to miss out on so much*

*(Petra, MND nurse: lines 30-33)*

This suggests that the process of creating the legacy may stimulate a sense of internal conflict for the plwMND. As previously suggested by Kirsty, Ada and Mark, plwMND want to '*not be forgotten*' by the young people in the future (pages 215-217). Yet, in order to achieve this and create a digital legacy, plwMND are faced with having to regularly consider their imminent death.

*I would think it is very painful, because of course, it's for when they're no longer here. And a digital legacy for key parts of that person's life, they won't be there to share in that moment so I'd have thought it would be very painful for them to have to do it.*

*(Willow, MND nurse: lines 29-31)*

Similarly, Ada reflected upon a plwMND she had supported in the past. She described that the patient experienced a sense of guilt as a result of her illness

and imminent death. Arguably, the creation of a digital legacy alleviated some of this guilt by providing the plwMND with a sense of being able to contribute to her children's future.

*I think sometimes, with young people [patients], there is a guilt, a guilt that they're dying because they're not going to be able to fulfil the normal role of parenting. I think that was [the case] with her, 'I'm not going to be here to help you get your mortgage. I'm not going to be here to help you do this, and I'm not going to be here to be a gran for your children' [...] And of course, that is the saddest possible thing to feel guilt, on top of all you're going through*

*(Ada, hospice chaplain: lines 48-56)*

However, it was also indicated that developing this future contribution for the young person's life through creating a digital legacy, provides additional challenges for plwMND with the planning of the content.

*It's a difficulty, isn't it? Because what are you, when you're in such an emotional place that you have to do this, as a parent or a grandparent or, whatever relative. How do you then decide which bits are important in terms of getting those messages down? [...] it's picking out the salient bits. So it is about picking out the messages that you would want to give to the young people that you feel are important for them to help remember you*

*(Rita, child bereavement researcher: lines 58-65)*

This resonates with earlier comments provided by Kirsty regarding the desired physical representation of the plwMND that is captured within the digital legacy (page 221). Yet in contrast to Kirsty, Rita emphasises the challenge of '*picking out the salient bits*' in order to create an accurate and desirable digital representation of themselves for the young person. The challenge of deciding upon the content of the digital legacy was similarly reinforced by Pam.

*[...] because it's about what do you keep in? What do you keep out? How do you want to represent yourself to them? So, I think that would probably be quite a [challenge], it wouldn't be quick necessarily to do*

*(Pam, child attachment researcher: lines 135-137)*

This challenge was reinforced from the findings collected with plwMND who had created a digital legacy. Tommy described this process as something ‘*really quite hard to do*’ (Chapter 6, page 158), and John outlined the challenge of knowing how to best convey the information being delivered in the legacy (Chapter 6, page 163).

### 8.2.3 - Practical challenges and barriers to creating a digital legacy

In addition to the various psychological challenges plwMND may face when creating a digital legacy, a number of physical barriers were also suggested. Of pertinence is the need for physical dexterity in order to use the necessary technological equipment.

*I suppose the actual practicalities of using equipment, obviously, because people with MND can have limited ability really when it comes to using technology, moving their hands etcetera*

*(Pearl, MND care advisor: lines 35-37)*

The need to be able to use technological equipment is a fundamental requirement for plwMND to create a digital legacy. This is clearly problematic for plwMND whose physical dexterity may have declined as a result of disease progression, as highlighted by John who outlined that using equipment was gradually ‘*getting harder*’ (Chapter 6, page 171). Thus, reinforcing the need for plwMND to begin creating their digital legacy in a timely manner before they

*'miss the boat'* (Rose, MND nurse: line 171). This was outlined as a key challenge by Tommy and Alice to creating their digital legacies (Chapter 6, pages 143-144). Kelly similarly referred to dexterity as a potential barrier for plwMND to create a digital legacy, but she also directed attention towards the person's speech.

*I think because obviously you've got the problems with how MND affects the person so in terms of they may have affected speech which will make recording something quite difficult. If they've got dexterity problems it might mean using a computer to generate a legacy by IT. Recording that maybe quite a challenge so it may be that they need additional support*

*(Kelly, MND children and young people specialist: lines 68-71)*

Evidently speech is another key element of the digital legacy which enables meaning and communication to be conveyed by the plwMND to the young person. Yet, if vocal abilities have declined due to disease progression, this aspect of the digital legacy will be impeded and provide additional challenges for plwMND. This provides further reinforcement for the need to begin recording the digital legacy *'as soon as possible'* prior to both physical, and vocal deterioration (Pearl, MND care advisor: line 44). There is arguably an optimal period of time between plwMND feeling psychologically ready to begin recording their digital legacy, and having the physical and vocal abilities to do so.

*And of course, then there's the physical thing of actually being able, if the speech is affected. Actually, getting them to do it at the right time because if their speech is affected, it's whether they can actually manage to do the recording*

*(Willow, MND nurse: lines 35-38)*

Lastly, an additional physical barrier builds upon the use of technological equipment in order to create the digital legacy. As previously mentioned by Pearl, reduced physical dexterity may hinder a plwMND's ability to create a digital legacy. Additionally, however, a lack of knowledge regarding how to use technological equipment may create challenges for some plwMND.

*The people that might want to do it, may not actually understand, technologically, how to do it. You know, they may just not be technically inclined or may not use pieces of equipment like that*

*(Kim, palliative care consultant: lines 89-91)*

This suggests that some plwMND may want to create a digital legacy, '*but may not know how to get started*' (Roxy, MND nurse, line 35). Therefore, obtaining some technological support may be crucial for plwMND who have limited knowledge or experience in using technological resources.

### **8.3 - Young people using a digital legacy**

This master theme encompasses the findings related to bereaved young people using a digital legacy created by a plwMND. This will consist of two superordinate themes; *benefits and value for young people using a digital legacy*, and, *challenges and barriers for young people using a digital legacy*. Both these themes encompass an additional five subsidiary ordinate themes which will be discussed in turn. In keeping with guidance provided by Smith (2011) in Chapter 5 (page 132), a summary of the distribution of themes across the sample is presented below in Table 9.

Table 9- A summary of theme prevalence.

	Superordinate theme	Ordinate theme	No. of participants	No. of references
Bereaved young people	Benefits and value for young people using a digital legacy	Promoting memory of the person and their voice	15	34
		Endorsing connection and continuing bonds	13	28
		Accessibility and usability	11	23
	Challenges and barriers for bereaved young people using a digital legacy	Providing and accessing the digital legacy	12	45
		Content of the digital legacy	11	20

### 8.3.1 - Benefits and value for young people using a digital legacy

It was suggested that using a digital legacy created by a plwMND may provide a number of benefits for bereaved young people. As such, three ordinate themes were evident which will now be discussed in turn.

### 8.3.2 - Promoting memory of the person and their voice

A key issue referred to throughout the interviews was that a digital legacy could provide a way to evoke and stimulate thoughts and memories of the plwMND. Moreover, the digital legacy may provide the bereaved young person with a sense of comfort due to offering a permanent and readily accessible way to see and hear the plwMND.

*I think if you've got something that is permanent, or relatively permanent, because if it's a digital thing that you can keep going back to. Children, I think when they're bereaved, my experience would be they get very upset at that thing that 'oh, I can't remember what they sound like. I can't remember what they look like.' And while you might think that's good, and normal process of moving through that grief process, you know that is distressing for some children. And I think they would probably find that quite comforting*

*(Pam, child attachment researcher: lines 99-104)*



This was further reinforced by Grace, a palliative care therapist, who suggested that much of the comfort in using the digital legacy would be attributable to *'hearing the person's voice again'* (line 118). This is clearly evident from the accounts provided by the bereaved young people in Chapter 7 (pages 188-192). However, Grace also inferred that comfort may only be obtained *'when you're in a good place, and you've gone through the grieving process'* (line 117). Arguably then, gaining a sense of comfort requires a passage of time in which the bereaved young person has reached this *'good place'* in their grief journey. This is likely to be highly individualistic for the young person with no definitive time-scale in which they will feel *'ready to visit'* (line 118) the plwMND through the digital recording. This resonates with findings from bereaved young people, Becky and Sophie, who similarly described the need for a passage of time before accessing such resources (Chapter 7, page 205). Grace also highlights that whilst the sound of the person's voice is an important feature within the digital legacy, the visual aspect of *'actually seeing them'* (line 120) is also valuable. Crucially, both elements of sight and sound combined, enable the bereaved young person to *'bring[s] back the memories'* of the plwMND (line 120).

Other participants similarly built upon this idea of the plwMND's recorded voice providing a sense of comfort and evoking treasured memories, thus reinforcing the findings provided by bereaved young people (Chapter 7, pages 188-192).

*I think research suggests that the first thing you forget when someone dies is the sound of their voice, and where we've got videos and we've got photographs and things which are really important, but to actually have that, hear that voice, reinforces a memory and, I think just is really important for people*

*(Rita, child bereavement researcher: lines 47-50)*

*I think people's voices, the memory of people's voices do go. You know, you can remember what people's faces look like, and you're much more likely to have a photograph of somebody, but the memories do go of the voice of family members. Sometimes when you hear that voice, it does take you back*

*(Petra, MND nurse: lines 17-19)*

Interestingly, it was also suggested that the recorded sound of a plwMND's voice may have beneficial use with both bereaved and non-bereaved young people. Willow reflected upon a plwMND she had supported in the past that had young children.

*I suggested that she recorded something and then their little babies could actually hear her voice while she was still there. So it may not sometimes always be used when they've passed away, it can be used while they're further down the disease progression. But I think it's just something for the children to hear that person's voice really*

*(Willow, MND nurse: lines 20-24)*

Arguably then, whilst the physical death of a plwMND creates the ultimate bereavement for a young person, the loss of physical abilities such as speech, may create a succession of bereavements for the young person. A digital legacy may therefore provide a sense of comfort by attending to just one of the many losses young people are likely to experience.

Like Willow, Kelly also highlighted the potential value of a digital legacy for young people while the plwMND is still alive. Kelly suggested that a digital legacy may be particularly useful for young people providing care for a plwMND who is experiencing cognitive changes such as frontotemporal dementia. As such, the plwMND may seem as if '*they're not the same person*' (line 87). She suggested that having a digital legacy may provide a way to

*'remind and 'reassure' (line 89) the young person of the plwMND prior to the onset of cognitive changes. Pertinently, the digital legacy 'reminds you of that relationship that you had' (line 91) with the plwMND, prior to onset of the disease and cognitive changes. This reiterates the importance of timely recording of the digital legacy during the early stages of the disease, as previously outlined by Willow (page 225). It is therefore crucial that the legacy not only captures the desired identity of the plwMND (Kirsty, page 221), but also represents a version that is accurate and desired by the young person using the recordings. With this in mind, creating a digital legacy prior to significant physical and cognitive decline, may provide the young person with an alternative memory of the plwMND. This will be focused more upon the positive memories recorded by the plwMND, instead of the negative recollections which were developed during the later stages of the disease.*

*[regarding the progressive nature of the disease] it eclipses the memories of them as a well person. So I think if you had this film, even if it is just this short clip, it would really help to remember the person and I think it would really help the bereaved people moving forwards.*

*(Rose, palliative care nurse: lines 72-75)*

An additional perceived benefit for bereaved young people using a digital legacy created by plwMND, was that it could assist in building a narrative of the person's life. It was suggested that *'a digital legacy would give them maybe a picture of what that person's life was like and what they shared with you'* (Kacey, child bereavement therapist: lines 48-49). Data collected with the bereaved young people highlighted this as an important feature of a digital legacy (Chapter 7, page 202). Consequently, the *'picture'* that the young

person develops is based upon the carefully selected material identified by the plwMND. Arguably then, there is a dual process whereby the plwMND is selectively recording memories of their past which, in the future, will shape the young person's knowledge of the plwMND's identity and narrative. Evidence of this can be gained from the accounts provided earlier by John and Alice. They described how they wanted their digital legacy to provide biographical information '*relevant to what [had] formed*' their identity and character (John, Chapter 6, page 147).

It was suggested that young people often have a natural curiosity for such biographical information. A digital legacy would therefore address this curiosity through providing a type of biography as told by the plwMND. This was described as important for bereaved young people (Becky, Chapter 7, page 202). Moreover, the legacy not only provides the young person with factual information regarding specific life events, but also conveys detail of what the plwMND was like, in terms of personality and character through the way it is delivered.

*I think it is so powerful to be able to have those [memories/stories], for the young people to be able to remember. And even if it's a younger child whose parent or grandparent has died, when they're older and they're actually more inquisitive about 'well, what was mum, dad, grandad like?' You know? 'What were they like when they got married?' And to be able to have that narrative and to be able to actually hear that from the person in terms of, a biography almost [...] So to be able to actually hear it from them*

*(Rita, child bereavement researcher: lines 40-47)*

### 8.3.3 - Endorsing connection and continuing bonds

An additional perceived benefit for young people using a digital legacy, was the idea of a continued bond or connection between the young person and plwMND.

*I'd have thought for children who have lost parents and they've got this digital legacy, like I said, it just keeps that thread, that reassurance that they were thinking of them so they can still touch base with mum or dad with using that digital legacy*

*(Willow, MND nurse: lines 58-61)*

Interestingly, Willow mentions that a digital legacy ‘*keeps that thread*’ between the deceased and young person. This is a pertinent analogy as it suggests that the digital legacy provides an elongated and delicate connection between the young person and plwMND. Prior to the plwMND dying, this relationship and connection would have been significantly more apparent than a piece of thread through daily interactions and communication. Moreover, a sense of connection may be bolstered due to the young person being aware that the digital legacy has been purposefully recorded for them by the plwMND.

*[The digital legacy is] something that's been created for them and it's a special thing, it's for them and that might be one of the last things they've got when that person [becomes ill/dies] [...] And because it's been created with intention for it to be there, that's very different to a present or something else. The intention of that person was that 'here's something for you, it's special to you, it's something for you to keep and for you keep hold of'*

*(Pam, child attachment researcher: lines 107-111)*

Similarly, Kelly also highlighted that watching the digital legacy would enhance a sense of connection and strengthen bonds with the deceased. This was due to the young person being *'able to keep that person in your life'*, albeit in a digital form (Kelly, MND children and young people specialist: line 112). Kelly also suggested that using a digital legacy *'would be helpful for a young person to actually go through the stages of grief in a much more healthy way'* (line 111). This was similarly reinforced by Sue, who described how plwMND can help *'to ease that loss'* and provide comfort for young people through leaving *'something of them'* (Sue, diversional therapist: line 119). The digital legacy therefore becomes this *'something'*, which enables bereaved young people to continue *'remembering that person and hearing their voice'* (Sue, diversional therapist: line 121). It provides bereaved young people with a sense of *'still being connected to them by watching or listening to them'* (Jess, child bereavement therapist, lines 52-53). A digital legacy was therefore likened to being a multi-dimensional object:

*A bit like a hologram really, isn't it? [...] You know, it's there and you can keep looking at it and it has that sense of being real. And you can sort of look at it from different angles and it's there for you to keep coming back to. It doesn't stop you living your life and I think it's important that people move on and live their life, but it's giving them that point of contact when they need it*

*(Sue, diversional therapist: lines 288-292)*

A digital legacy could therefore provide an alternative platform for bereaved young people to continue *'having that interaction, and being able to communicate, differently, but still having that together time'* (Rita, child bereavement researcher: lines 22-23). Similar to Willow then, Rita suggests that the actual content of what is recorded is not always pivotal for the

perceived value of the digital legacy. Moreover, a digital legacy enables people to *'communicate, albeit in a different form'* (Rita: line 20). This infers that communication continues to be an active and dynamic process between the young person and deceased plwMND when they are using the digital legacy. According to Kacey, the digital legacy may provide young people with a sense of *'comfort, you know? Being able to continue that connection, or have that bond'* (Kacey, child bereavement therapist: lines 24-25), even when the plwMND has died. This was clearly evidenced within Sophie's account of using a video legacy in Chapter 7 (page 194).

#### 8.3.4 - Accessibility and usability

A final perceived benefit of a digital legacy for bereaved young people, was regarding the accessibility and usability of the resource. Of importance was that a digital legacy would be a tangible and physical resource to be used by a bereaved young person.

*[young] people will have something concrete that they can turn to for when they're feeling or when they're experiencing some grief. Or when they just feel that they want to get close to the person that they've lost.*

*(Pearl, MND care advisor: lines 82-84)*

Additionally, the digital format of the legacy would lend itself to young people being able to access it independently, a point reinforced by Sophie (Chapter 7, page 200). This highlights a sense of autonomy and control for the bereaved young person, allowing them to use the digital legacy whenever they deem it appropriate.

*In the grief journey, there's things that you don't want to do in the first week, first month, first year. And some of it may be that you don't actually want to look at digital legacy for a little bit and you want to get on with your grieving, but it's always there. But the fact it's there doesn't mean you have to do anything, you're in control of it, aren't you?*

*(Mark, hospice chaplain: lines 57-60)*

Like Mark, Roxy also emphasised the benefit of a digital legacy being available to use at a time that is most appropriate for their unique grief journey. Poignantly, Roxy mentioned that *'they may not want to listen to it immediately, it might be too raw, too upsetting'* (MND nurse: line 94), suggesting use of the legacy might be more appropriate for young people further along in their grief journey. This resonates with findings from Becky and Sophie, who similarly described the need for a passage of time before accessing such resources (Chapter 7, pages 205-207). However, Roxy also suggested that *'just knowing it's there'* may provide a sense of comfort knowing it is available for a potential *'day that they just want to know something'* about the plwMND (line 95).

This concept of a digital legacy promoting a sense of independence and control for a bereaved young person was similarly reinforced by Petra:

*They could listen themselves, they don't need somebody else going through, if it is a family story or something like that, they can listen to it where and when they want to. On their own if they want to, or with other family members if they want to. It makes it a little bit more flexible for them to be able to remember the person at their own pace, and in an environment that they want to remember them in as well.*

*(Petra, MND nurse: lines 98-102)*

The sense of flexibility uniquely afforded by digital technologies was also described. It was noted that a limitation of physical items such as memory boxes, is that they are *'very physical, and you have to take it with you'* (Kirsty,



*palliative care consultant: lines 187*). In contrast, stimuli created and stored in a digital format, provides a way of *'accessing them really easily, potentially wherever you are. So, actually, you could have little things recorded on your phone, couldn't you? [...] that could be a real comfort (Kirsty, palliative care consultant: lines 185-186)*. This was suggested to be able to provide young people with *'an opportunity to self-soothe' (Kelly, MND children and young people specialist: line 120)*, and offer a sense of security knowing that the digital format means that *'it's always there' (Mark, hospice chaplain, line 58)*.

#### 8.4.1 - Challenges and barriers for young people using a digital legacy

The fourth superordinate theme identified from the interviews with participants, was regarding the various challenges and barriers for a young person using a digital legacy. These primarily fall in to one of two ordinate themes which will be discussed in turn; *providing and accessing the digital legacy*, and, *content of the digital legacy*.

#### 8.4.2 - Providing and accessing the digital legacy

It was suggested that a key challenge for a bereaved young person using a digital legacy, was the possibility of feeling pressurised to use the resource prematurely. Mark, a hospice chaplain, described how young people may *'really feel [that they] need to watch this' (line 62)* due to an awareness that it had been specifically created for them. As such, the young person might *'be a little bit pressurised'* into using the digital legacy, when they are *'not necessarily [at] the right part of the grief journey' (Mark, line 63)*. Similar to

Willow then, who inferred there to be an optimal period in which the digital legacy is created by plwMND (pages 225-226), there may be a similar period of use by the young people. Premature use may cause overly emotional or harmful reactions for the young person, simply due to them 'not being ready'.

*Sometimes it's very, very difficult, it could be very difficult for them to see, the person. You know, sometimes people, even children, are not ready. So there's that denial process that they cannot go there. So that could be quite difficult sometimes, for them to have to see the person, if they're watching them on a video or something like that*

*(Jess, child bereavement therapist: lines 54-57)*

Extending this further, the digital legacy could act as a negative reminder for the young person that the plwMND has died.

*We do know cases, for example, where parents have written birthday cards for every birthday up until they're 18. And actually, for some children that sounds like it's a lovely idea, but after the first couple, they don't really want them anymore [...] They want to be able to move on and not feel that sadness every birthday. They know it's there but they don't necessarily need that concrete, tangible reminder of it*

*(Pam, child attachment researcher: lines 42-48)*

Mark went on to suggest that this sense of pressure to use the digital legacy could be alleviated through some initial groundwork by briefing the young person of the content. This would allow the young person to rationally consider when and how will be most appropriate for them to access the digital legacy.

*I think telling somebody that you're doing a digital legacy, telling those that you love that you've done it, and that there's nothing in there for you to be worried about, there's no instructions in there, there's nothing that you need to know immediately, it's just my feelings about [name], my feelings about quality of relationship, my feelings about whatever it is. I think there's just got to be an honesty and openness about what it is*

*(Mark, hospice chaplain: lines 80-84)*

Pam also reinforced this notion of groundwork through emphasising that the young person possesses an understanding and choice '*about whether they access it or not, and actually, if you don't want to, that's okay, you're not being disrespectful or rejecting*' (child attachment researcher: lines 56-57). The young person should therefore be made aware that there is no prescribed or essential usage of the digital legacy. This was further reinforced by Rita who described the importance of groundwork to acknowledge the young person's developmental understanding and acceptance of the plwMND's death.

*For me there are the issues there in terms of, how it is handled very, very sensitively and being aware of the children's understanding that that person can't come back and isn't coming back and this is [DL] not them talking from beyond the grave, 'it's something that they've done before they've died, and do you remember when we did this, and you were there at the time'. So they're fully, aware of that and it's not going to be something almost like [gasp] I didn't expect to hear that voice again, where you know, where are they, why aren't they here with me, where's that voice coming from?'*

*(Rita, child bereavement researcher: lines 127-133)*

It was therefore suggested that withholding access to the digital legacy may be appropriate for some bereaved young people until they are deemed developmentally ready. Similar to Mark, Grace suggested there to be an optimal period in which the digital legacy would be beneficial.

*I don't think it should be given initially, I think you've got to give that child room to grieve, and that can take a long time. And then introduce it to them as 'you have it, and it's theirs for whenever they want to visit it'. But have somebody with them when they visit it because that can be very, very stressful as well. So I, at that point, would hand it over to the child and give the child the rights to decide, when they want to do it. But the grieving process can take an awful long time and I think you've got to let them go through that grieving process before it's then introduced*

*(Grace, palliative care therapist: lines 97-104)*

#### 8.4.3 - Content of the digital legacy

A final perceived challenge and barrier for young people using the digital legacy, was centred upon the actual content of the recordings. Of pertinence, was the idea that the digital legacy would provide evidence and a reminder of the plwMND's illness due to their physical appearance in the videos. This resonates with earlier comments provided by Kirsty and Pearl (page 221), who described this as a potential challenge for plwMND. It was similarly highlighted that watching a digital legacy which featured a plwMND with advanced deterioration, may be somewhat traumatic and evoke negative memories for the young person. As such, the digital legacy could stimulate disease related memories of the plwMND, instead of the intended positive ones.

*Makes it all flood back in a way. It takes them back to that time when it was a bad time for illness because as you know, with MND, it can be quite traumatic I'm sure if you're a child, to see mum or dad deteriorating like that*

*(Willow, MND nurse: lines 67-68)*

*My only thing would be if you do any filming of people, particularly in people with both cancer or motor neurone, I think it's best to film them when they're looking fairly okay and fairly well, because it would be quite difficult I think to go back on seeing how the downfall came.*

*(Grace, palliative care therapist: lines 10-12)*

Furthermore, an additional challenge for bereaved young people using the digital legacy, may be that inaccurately represents the relationship once shared with the plwMND. This resonates with earlier comments provided by Pam, Grace and Rita, which described the challenge for plwMND in recording an accurate and desirable representation of themselves (pages 222-223). In

contrast, am noted that whilst the plwMND may feel that they have recorded an accurate version of themselves, the bereaved young person may feel differently.

*I think there is also that assumption, I guess underlying all this, that those parent child relationships are all lovely and harmonious and everything that we would wish them to be. Whereas, what we know is the reality is, that's not always the case [...] If you've had somebody who's been quite difficult and then you've got this lovely 'let's play happy families' thing, which is sometimes, I think, a bit of a pressure when you've got a terminal illness in the family*

*(Pam, child attachment researcher: lines 60-70)*

Finally, it was also suggested that the recorded sound of the plwMND's voice may create additional challenges for a bereaved young person. This is of interest due to being outlined by Grace, Rita, Petra and Willow, as one of the fundamental benefits of a digital legacy (pages 227-231). In counterbalance, however, hearing the sound of the plwMND's voice '*could actually be really quite distressing*' for some young people (*Rita, child bereavement researcher: line 92*). This was reinforced by Jess, a child bereavement therapist:

*It depends on, how you connect with your own senses, is what's going through my mind [...] that could give a lot of comfort to hear the person. But it could also, bring up those painful emotions that they may not want to go there, because it makes them realise that the person has died and, they're no longer with them*

*(Jess, child bereavement therapist: lines 88-91)*

Arguably then, comfort from hearing the plwMND's voice through using the digital legacy depends upon how the young person uniquely '*connects with [their] own senses*'. Some young people may find hearing the person's voice provides them with a sense of comfort, whilst visually seeing the person might be somewhat challenging. This might be the opposite for some other young

people who connect more with their visual senses and find the sight of the plwMND more comforting than the sound of their voice. With this in mind, the use of the digital legacy must be in accordance with the young person's wishes to ensure it provides comfort rather than '*bring[ing] up those painful emotions*' (Jess, child bereavement therapist, line 90). Consequently, there is scope for the digital legacy to be used in accordance with the young person's unique preferences whereby either the visual or audio aspect could be temporarily blocked, thus promoting a sense of comfort and reducing any sense of it being '*traumatic for them*' (Kacey, child bereavement therapist, line 209). It is therefore crucial to '*listen to what they need*' in order to provide the most appropriate support for each individual young person (Jess, child bereavement therapist, line 134).

## **8.5 - Summary**

In this chapter I have described the findings generated from the interviews conducted with healthcare professionals, specialists and experts regarding their perceptions of the use of digital legacies with people affected by MND. These findings have been categorised into four superordinate themes with an additional nine ordinate themes. Themes were developed from a consensus across all participants in line with recommendations by Smith (2011). The following discussion chapter will synthesise findings from all three findings chapters. I will additionally provide contextualisation of the key findings presented in these findings and relate to existing theoretical and empirical literature.

## Chapter 9 - Discussion

“Instead, he would make death his final project, the center point of his days. Since everyone was going to die, he could be of great value, right? He could be research. A human textbook. Study me in my slow and patient demise. Watch what happens to me. Learn with me.”

Mitch Albom (‘Tuesday’s with Morrie’- 1997)

The purpose of this chapter is to provide a synthesis and discussion of findings generated from the study. The chapter will begin with a brief overview of ‘The Model of Reciprocal Bonds Formation’. This is a new model which has been developed from the data generated by this study. In order to fully describe the applicability of this new model, it will be broken down into individual concepts which will form the structure of this chapter. Existing theoretical and empirical literature will be provided in relation to key findings from the study in order to highlight similarities and differences with current knowledge. The final section of the chapter will summarise the key original contributions to knowledge that have developed from this study.

### 9.0 - Overview of ‘The Model of Reciprocal Bonds Formation’

As described throughout Chapter 3, the continuing bonds model of grief suggests that bereaved young people seek to retain a sense of a continued connection with the deceased (Silverman, Klass and Nickman, 1996; Madison, 2005). Based upon findings from this study, it was suggested that use of a

video-based digital legacy could provide a platform for bereaved young people to remember the deceased, and also instil a sense of comfort. Furthermore, the use of a digital legacy provides young people with a platform to gain biographical information about the life of the plwMND, their personality, and identity. As suggested by Walter (1996), obtaining this knowledge promotes the opportunity for people who are bereaved to develop a 'last chapter'. This information therefore contributes to the development of a 'durable biography', thus allowing the bereaved to *'find a stable place'* for the deceased in their life (Walter, 1996, p.13). Similarly, Fearnley (2015) described the importance of developing a 'penultimate chapter' which features information regarding the person's illness. This penultimate chapter is therefore created before the person living with a terminal illness has died. Following death, the bereaved will later synthesise this penultimate chapter with the last chapter to create a holistic understanding of the deceased's life.

However, a current limitation of these existing bereavement models is that there is no consideration of how the person living with a terminal illness may contribute to, and influence the development of, that durable biography. According to existing theories, the deceased are entirely passive in how this biography is developed by the bereaved. In contrast, findings from this study highlight that plwMND might also become active contributors to shaping this durable biography. In creating what I coin an 'autobiographical chapter', through recording a digital legacy, plwMND can purposefully record information which will actively contribute and shape the young person's

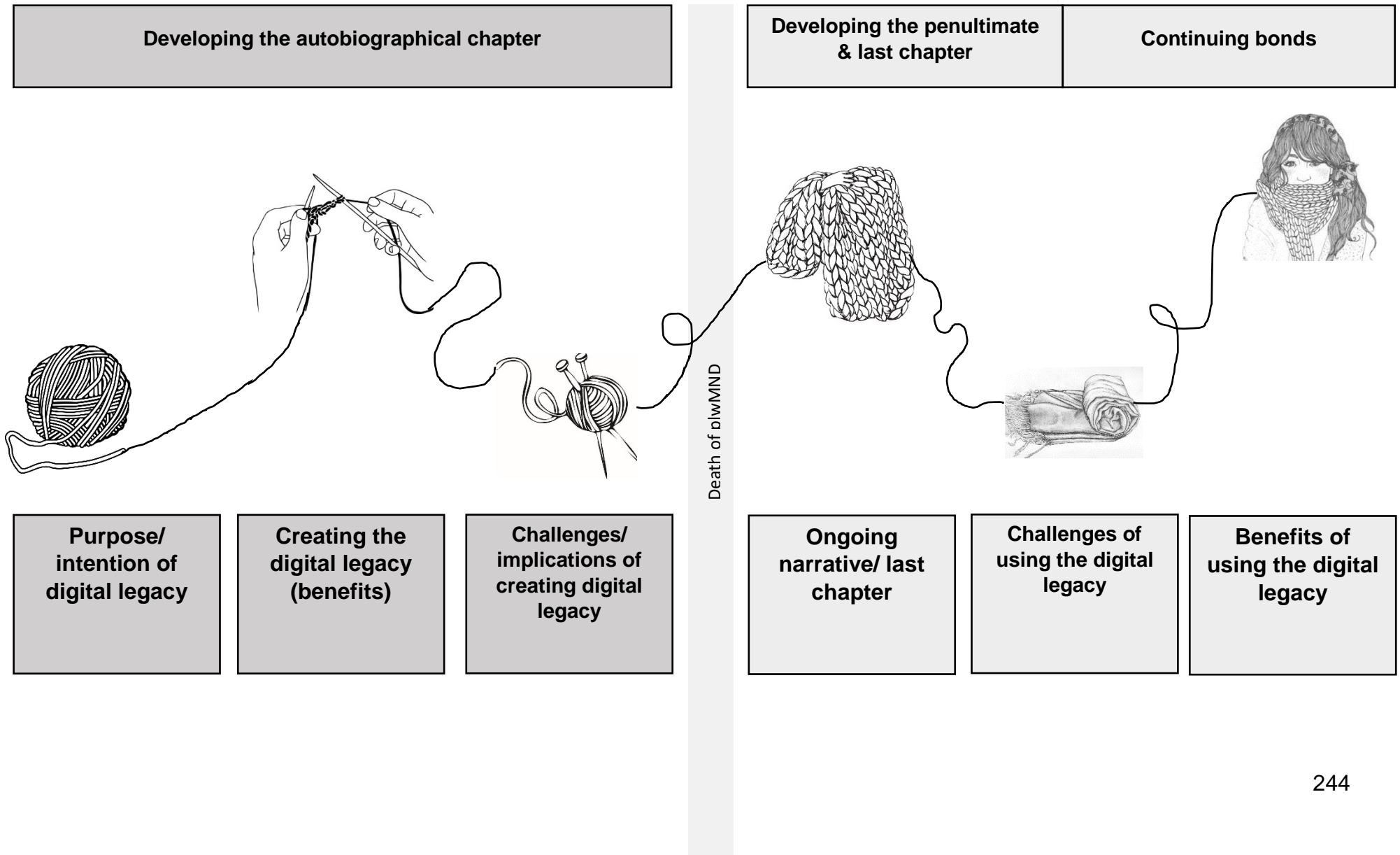


durable biography regarding themselves and their life. Furthermore, it is argued that an autobiographical chapter in the form of a digital legacy, provides a number of mutual benefits for both bereaved young people using the legacy, and plwMND creating it.

As such, 'The Model of Reciprocal Bonds Formation' which has been developed from this study, highlights the need for a third type of chapter, an autobiographical chapter. Within this study, the newly coined autobiographical chapter, is purposefully created by the plwMND through recording a digital legacy. It is suggested that the autobiographical chapter, like the penultimate and last chapters, contributes to the development of a durable biography regarding the deceased. However, unlike the last chapter which is written by the bereaved after the person has died, the proposed autobiographical chapter is purposefully created by plwMND before their death. It is argued that this autobiographical chapter becomes a resource which features a wealth of information to stimulate and inform the bereaved young person during their creation of a last chapter. Like Fearnley (2015), the information included within the autobiographical chapter will be drawn upon, and synthesised by, the young person to develop a durable biography regarding the deceased. Additionally, however, it is argued that use of this autobiographical chapter in the form of a digital legacy, further promotes a sense of continuing bonds with the deceased by the bereaved young people. This is due to the young person gaining a sense of comfort when watching the videos and learning about the plwMND's life, values, identity and character.

In accordance with the interpretative nature of IPA (Smith, Flowers and Larkin, 2009), an illustrated analogy was developed to provide clarity for 'The Model of Reciprocal Bonds Formation' and applicability of an autobiographical chapter. This was stimulated by a quote provided during the interviews with healthcare professionals, specialists and experts suggesting that digital legacy allows bereaved young people to '*keep that thread*' with the plwMND (Willow, MND nurse, Chapter 8, page 232). As depicted in the illustration below (Figure 16), the 'thread', as a raw ball of wool, is carefully knitted by the plwMND into an item that will ultimately provide the bereaved young person with comfort. Throughout the process of 'knitting' the digital legacy, the plwMND intertwines aspects of their biography, personality and identity within their autobiographical chapter, which the young person will later utilise to develop their last chapter and durable biography (Walter, 1996). Of pertinence, however, the process of 'knitting' the digital legacy, and therefore, the autobiographical chapter, has notable importance for the plwMND even before the bereaved young people access it. Each of the interpretative illustrations which are presented below, indicate the key overarching themes which will form the structure of this discussion chapter.

Figure 16- Overview of 'The Model of Reciprocal Bonds Formation'



## 9.1 - Autobiographical chapter (plwMND)

The following section of this chapter will focus upon the findings related to plwMND creating a digital legacy. This will begin with a theoretical discussion regarding the purpose of the digital legacy to provide a type of symbolic immortality for plwMND. Following this, a more practical discussion will be directed towards the various benefits and challenges for plwMND in creating a digital legacy.



### 9.1.1 - Purpose and intention of the digital legacy

As with the ball of wool having an underlying purpose to be knitted into a new product, the digital legacy had a similar potential for plwMND. Of pertinence was that the digital legacy would provide a way for plwMND to capture and convey important information which they wanted young people in their family to know about them. Yet, like the wool, the way in which this information was captured within the digital legacy and ‘knitted’ together, was multifaceted. It was clear from this study that an underlying purpose of the digital legacy was to provide a platform upon which young people could learn about the plwMND. This is supported by existing literature regarding the creation of broader legacies which are normally centred upon biographical information (Montross, Winters and Irwin, 2011). Moreover, the digital legacy ensures that plwMND would still have ‘*input in [the children’s] life*’, even after they had died (Alice, Chapter 6, page 151). This inferred a sense of the plwMND being able to continue parenting in some way after their death when the young person accesses the digital legacy in the future to construct their durable biography. In essence, the digital legacy provided the

plwMND with a sense of comfort in knowing that their autobiographical chapter (the digital legacy) would provide a type of substitution for their physical presence. As described by Tommy, the digital legacy would offer '*a baseline*' for his children to develop their own ideas and concepts (Chapter 6, page 153). This is arguably something which is central to the role of being a parent - *to provide your child with the necessary skills, information and knowledge for life*. Yet, due to having a terminal illness, like MND, opportunities become limited to develop this knowledge and skills within children. In normal parenthood, knowledge would be delivered to children on a 'need to know' basis which is commonly initiated by the young person. However, plwMND are aware that they will not be present in the future when the young person may seek this information. Consequently, the digital legacy has been recorded in preparation for future periods in time when the young person may seek information from their parent or grandparent. This further reiterates the new concept of an autobiographical chapter being provided by the plwMND in the form of a digital legacy, thus enabling the young person to later develop their durable biography. As suggested in existing literature (Vitale and Genge, 2007), this seemingly provided plwMND, in this study, with a sense of comfort in knowing that they would still be useful and able to contribute towards their child's life, even after they had died.

Similarly, the digital legacy provided a platform for plwMND to convey their unique biographical narrative to young people in their family. As suggested by John, the digital legacy captured information which was '*relevant to what has formed me*' (Chapter 6, page 147). This included the sharing of biographical

information and particular life experiences which plwMND had deemed influential in their lives. Thus, when using the digital legacy in the future, the young person could learn about the plwMND's life narrative, and begin to understand how they became the person they were, before they died. This finding is reinforced by existing literature regarding the creation of broader legacies (Allen, 2009). Additionally, however, the digital legacy captured more *implicit* information such as the plwMND's identity and character within the newly coined 'autobiographical chapter'. This was often provided through 'hidden' messages within the digital legacy, such as humour, due to the way content was delivered. For example, it was important for Charlie to convey his comical personality to future grandchildren and great niece(s)/nephew(s) – hence he used a costume and props to deliver his children's story. Whilst it was important for plwMND to convey their personality within the digital legacy, similarly, bereaved young people gained a sense of comfort from learning about it. This suggests that the capturing of personality within the digital legacy provides mutual benefits for both the plwMND who create it, and, the bereaved young people who use it.

This idea of the digital legacy transferring information regarding the plwMND's life, personality and identity, resonates with the previously described concept of biological/physical symbolic immortality (Lifton, 1979) (Chapter 2). It is suggested within this theory that people approaching death have an innate desire to convey their thoughts, values and memories to future generations. For some people, biological/physical immortality may be achieved through

acknowledgment of passing genetic information to their children and future generations in the form of DNA. In essence, this creates a type of physical immortality through perceiving that unique characteristics will be passed to future generations through biological traits (i.e. same eyes, hair colour, body shape). However, the findings from this study also infer that plwMND will become '*biologically* immortalised' within future generations, as a result of the digital legacy transferring information between the deceased and bereaved. Furthermore, the process of creating a digital legacy also resonates with Lifton's notion of '*creative* immortality' whereby the digital creation, i.e. the digital legacy, can be passed on to future generations to influence and guide the young people. Similar findings have been reported in the broader life review literature. One such study, conducted by Ando, Tsuda and Morita (2007), outlined that people gain a sense of comfort in knowing that their legacy will provide a continuation of self within their children and grandchildren.

The consideration and application of symbolic immortality by creating a legacy has been proposed by existing literature, and noted to alleviate an element of existential concern for people with a terminal illness (Rosenbaum et al., 2006). However, unique to this study, is that a digital legacy captures additional elements of the plwMND's identity such as the sound of their voice, their personality, and mannerisms. This is of pertinence due to the person's autobiographical chapter (the digital legacy) providing information which is complementary to the more physical traits associated with biological/physical immortality. It is therefore argued that a digital legacy provides an additional

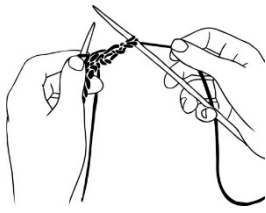
sense of symbolic immortality for plwMND compared to more traditional written legacies. Moreover, this additional information provides an alternative source of knowledge which the young person can later 'knit' into their durable biography of the deceased.

In addition to a digital legacy providing a sense of symbolic immortality, it is also argued that creating the legacy helped plwMND to cope with their imminent death (Cadrin, 2006). The task-based approach to dying highlights the need for people approaching death to undertake tasks in four distinct domains of their life; physical, psychological, social and spiritual (Corr, 1992). The process of creating a digital legacy attends to each of these tasks for plwMND. Of pertinence is that plwMND are able to engage in a *practical task*, that is in keeping with their declining physical capabilities, to create a digital legacy. This promotes the idea of plwMND becoming engaged with activities which focus on the '*here and now*' and provide a '*fine focus on what they can still do*' (Rabbitte, Bates and Keane, 2015, p.305). In doing so, plwMND also carry out *psychological tasks* through developing an acceptance of their imminent death. As suggested by Noble and Jones (2005), *psychological tasks* often overlap with *social tasks* which include making provision for loved ones who will be left behind after the plwMND has died. Within the current study, this 'provision' is the autobiographical chapter in the form of a digital legacy which the plwMND has recorded for the young person. Lastly, Corr (1992) emphasises the need for people who are dying to engage with *spiritual tasks*. This may be atonement for previous actions throughout their life, feeling closer to religion, or, retaining a sense of purpose and feeling useful to others.



The last of these spiritual tasks is clearly apparent within this study of plwMND creating a digital legacy, thus responding to calls from the European Association for Palliative Care (EAPC) for practical ways in which spiritual care can be bolstered for people who are living with a terminal illness (Holloway et al., 2010; Paal, Leget and Goodhead, 2015). Similar findings of creating a legacy to enhance feelings of purpose and value for people with a terminal illness has also been highlighted in the broader legacy creation literature (Ando et al., 2010; Hall et al., 2012; Kwan, Ng and Chan, 2017).

In accordance with Corr's task-based theory (1992), creating a digital legacy provides a way in which plwMND can undertake necessary tasks from each of these key domains. The creation of a legacy not only promotes a holistic approach to coping with death and dying (Noble and Jones, 2005), but it may also provide a sense of autonomy and control for the plwMND regarding when they choose to engage with the tasks. As such, a digital legacy provides an opportunity for plwMND to record something which is fitting for their unique demands. This means the digital legacy could be something as short as a recorded story (Charlie), or perhaps more substantial, like a compilation of biographical videos (Tommy and John). Consequently, there is flexibility in the choice of type of digital legacy which can be recorded. This is something unique to creating a digital legacy which more structured reminiscence interventions do not tend to provide.



### 9.1.2 - Benefits in plwMND creating a digital legacy

The process of creating or ‘knitting’ the digital legacy provides a number of benefits for plwMND. It was noted that the disease had caused ‘*a feeling of helplessness, and not feeling that they’ve got any purpose at all*’ (John, Chapter 8, page 174). This idea of lacking a sense of purpose in life has been recognised to contribute to feelings of hopelessness in plwMND (Plahuta et al., 2002; O’Brien and Clark, 2015). However, consistent with existing literature regarding the creation of broader legacies, (Chochinov et al., 2005; Allen et al., 2008; Hall et al., 2011), recording a digital legacy instilled a new sense of focus and purpose in life for the plwMND by having a project to complete through which they could redirect, and channel, their efforts. This is of importance as current literature regarding the creation of legacies, suggests keeping occupied, with achievable goals and tasks, to be beneficial for people with a terminal illness (Vitale and Genge, 2007; Fanos et al., 2008; Allen et al., 2009). It was also clear that the digital legacy provided plwMND with a platform to reaffirm their life role as a parent or grandparent and continue to guide and influence the young person after they had died. This reaffirmation of roles has been described as providing a comforting sense of ‘*parenting beyond the grave*’ (Saldinger et al., 2004, p.932), and a means to bolster a sense of spiritual wellbeing for people approaching death (Ando, Tsuda and Morita, 2007; Ando et al., 2008).

Similarly, it was found that creating a digital legacy provided plwMND with a new sense of meaning and purpose to life. This is of pertinence as it has been well documented that plwMND often feel that life becomes lacking in meaning and purpose following their diagnosis (Centers, 2001; Averill, Kasarskis and Segerstrom, 2007; Foley, O'Mahony and Hardiman, 2007; McLeod and Clarke, 2007; O'Brien and Clark, 2015). PlwMND often seek new and alternative ways to find meaning in life (Fanos et al., 2008). The idea of a digital legacy attending to this concern for plwMND, also resonates with existing literature regarding the creation of more traditional legacies (Chochinov et al., 2005; Allen et al., 2008; Ando et al., 2008; Hall et al., 2011; Houmann et al., 2014; Vukasnovic et al., 2016; Wang, Chow and Chan, 2017). However, findings unique to this study emphasise that creating a digital legacy may have additional longer term benefits for plwMND. Becoming engaged with creating a digital legacy may bolster self-confidence and provide a sense of purpose and enjoyment for plwMND. Furthermore, recording the digital legacy may also provide a sense of cathartic relief for plwMND in providing an opportunity *'to say the things that you wanted to say; to give that back-up, if you're not able to say them'* (Mark, hospice chaplain, Chapter 6, page 219).

Consistent with existing literature regarding people approaching the end of life creating a legacy, plwMND also benefited from reminiscing and reflecting upon past memories and achievements (Cadrin, 2006; Sato, 2011; Keall, Clayton and Butow, 2015; Kogan et al., 2017). Whilst it was clear that plwMND wanted to provide recordings for future milestones in the young person's life, similarly,

they also wanted to document past milestones of their own life. This required them to reflect on key biographical events and achievements throughout their life, and evaluate whether to include them or not. These memories would be included within the digital legacy, and therefore their autobiographical chapter, if they were recognised as conveying an element of the plwMND's identity or narrative that could later be synthesised into young person's durable biography.

Additionally, some memories, or stories, recorded within the digital legacy possessed an underlying life lesson or message with moral value. For example, Tommy described a life lesson within his digital legacy regarding '*moving up in life*' and '*bettering himself*' after leaving school with no qualifications (Chapter 6, page 176). Delivering life messages was also apparent in the literature for people who were involved in life review interventions (Ando et al., 2012). Findings from this study also suggest that plwMND may resolve negative illness-related perceptions through reflecting upon past memories and 'remapping' their life. This resonates with the concept of reminiscence whereby people engage in a crucial task of '*making sense of the life they have lived*' (Butler, 2002; p.1). The desire to create a digital legacy for a young person in the family, therefore stimulated plwMND to reminisce and evaluate their life, thus preparing them for death (Butler, 2002). In keeping with existing literature, it was found within the current study that this period of reflection could also provide a sense of self-transcendence for plwMND (Centers, 2001; Fanos et al., 2008; Ando et al., 2009). The findings indicated

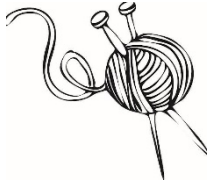
that plwMND could almost re-experience their life before onset of the disease through reflection, thus temporarily transcending beyond symptomatology (Redhouse, 2014), which resulted in an improved sense of wellbeing (Real et al., 2014).

An additional finding from the study was that creating a digital legacy provided plwMND with a sense of control and independence over their life due to the process of recording their legacy. Feeling in control of life has been suggested to reduce the prevalence of anxiety and depression in plwMND (Jakobsson Larsson, Nordin and Nygren, 2016), and be indicative of positive coping strategies (Montel, Albertini and Spitz, 2012). The use of digital technologies to create their legacy meant that plwMND could record their legacy at a time and pace of their choosing. As such, they did not require the support of other family members, carers or therapists in order to create their legacy. This is poignant as existing literature suggests plwMND often feel a sense of hopelessness due to having an increased reliance upon others as the disease progresses (Plahuta et al., 2002; Felgoise et al., 2010). Moreover, this finding responds to calls from existing literature which suggests the need for a more streamlined and efficient approach to implement reminiscence work with people approaching the end of life (Donato et al., 2016; Bentley et al., 2017; Martinez et al., 2017).

Specifically, previous research conducted by Bentley et al. (2014) investigated the feasibility of dignity therapy with plwMND. This outlined that a key limitation of the intervention was the need for a trained dignity therapist, which was

demanding in time, thus making it financially costly. Similar findings have also been reported from interventions with non-MND populations (Hall et al., 2011). Therefore, creating a digital legacy negates the involvement of a facilitator, and transcription, thus highlighting it as a cost-efficient alternative for plwMND to carry out independently (Bernat et al., 2015). Furthermore, the findings of this study highlight that plwMND became motivated to begin creating their legacy at different points throughout the disease trajectory. Being able to record a digital legacy independently, without the need of a facilitator, ensures that the plwMND can begin recording at a point in time which is appropriate for them.

Lastly, the flexibility afforded by creating a digital legacy means that plwMND are able to 'unpick their knitting', and therefore, redo recordings, whenever they deem it necessary. This contrasts with existing interventions such as life review and dignity therapy, which require essential input from facilitators. In these instances, the legacy is somewhat 'fixed' after being compiled by the facilitator, meaning it is hard for the patient to add, modify or remove content after they are given the legacy document. Existing literature also highlights that sometimes facilitators may misinterpret information, or inappropriately compile and edit the legacy document (Lindqvist et al., 2015). Additionally, people may be reluctant to request changes to their legacy due to being aware of the time and cost involved for the facilitator to carry out the edits (Hall et al., 2012). In contrast, findings from this study highlight that creating a digital legacy independently from a facilitator, provided the opportunity to carefully edit and compile content in accordance with the plwMND's unique wishes and intentions of their digital legacy.



### 9.1.3 - Challenges and implications for plwMND creating the digital legacy

The process of 'knitting' the digital legacy was also found to create a number of challenges for plwMND. Most prominent was the idea of there being three 'windows of opportunity' for plwMND to record their digital legacy. This concept is an additional element to the new 'Model of Reciprocal Bonds Formation' which is particularly associated with the challenges in creating a digital legacy. This was firstly acknowledged from the perspective of there being a '*physical window of opportunity*'. A level of dexterity was an essential requirement for plwMND to use technological devices and create their digital legacy. Similarly, a '*vocal window of opportunity*' was identified whereby plwMND were still able to speak without significant deterioration of their speech. This was similarly identified in a study of dignity therapy with plwMND (Bentley et al., 2014). This was an important consideration due to speech being the main vehicle to transfer information, knowledge and meaning within the digital legacy. Lastly, a '*psychological window of opportunity*' was described whereby plwMND had reached a level of acceptance of their illness and their own mortality. This ensured that they were able to begin thinking about the future and their absence from the young person's life.

Somewhat of a challenge with these windows of opportunity is that, often, they may overlap. For example, a plwMND may reach a level of acceptance and be psychologically ready to begin their digital legacy, only after they have lost

physical dexterity. Consequently, they are unable to use the technological equipment to record their digital legacy. Moreover, they may have both the physical and vocal abilities to record their digital legacy, but perhaps not be psychologically ready to begin. This was reinforced through the concept of plwMND *'missing the boat'* (Rose, Chapter 8, page 220) whereby psychological readiness to create the digital legacy could be surpassed by physical and vocal deterioration.

In accordance with existing literature regarding plwMND creating a legacy (Aoun, Chochinov and Kristjanson, 2014), it was clear that a digital legacy must be recorded in a timely way to maximise the potential of each window of opportunity. As suggested by John, the recording of the digital legacy should begin *'very soon after being diagnosed ... [as] you don't know how fast it's going to progress'* (John, Chapter 6, page 142). Consistent with literature on dignity therapy for those with a terminal illness (Houmann et al., 2014), it would be beneficial for plwMND to be informed of the potential to create a digital legacy within the period shortly after diagnosis, when hopefully both physical and vocal windows of opportunity are open. However, it is also recognised that psychological readiness may only occur later on in the disease trajectory. As such, it is deemed appropriate to *'plant the seed'* early in the disease trajectory, meaning plwMND could come back to it later on when they were ready (Kim, Chapter 8, page 220). This highlights the potential benefit of including discussions about recording digital legacies within advance care planning for plwMND and patients with alternative terminal illnesses.



Of further consideration was the challenge for plwMND to record a desirable representation of themselves within the digital legacy. It was found that plwMND have a wish as to how they want to be remembered in the future by the young people. In contrast to Fearnley's idea of a penultimate chapter (2015), the plwMND did not want to be remembered for disease-related symptoms. This was enabled by recording the digital legacy early on in the disease trajectory, prior to significant onset of symptoms. Like traditional written legacies, it was hoped that this digitally recorded version of themselves would be the main platform used by the bereaved young people, in the future, to develop their durable biography (Lindqvist et al., 2015; Sposato, 2016). Yet, this finding reinforces current literature which highlights the challenge of identifying appropriate information and biographical detail to be included within the legacy (Hall et al., 2012).

An additional challenge for plwMND in creating a digital legacy was found to be the planning and preparing of content. It was noted that deciding upon the specific content to be included was extremely challenging. Of prominence was trying to predict what might be useful for the young person to know about the plwMND in the future, in order to support their development of a durable biography. Added to this was a pressure in the way that information was conveyed. The plwMND found it hard to record videos that were specifically directed towards the young people in response to unprompted topics or questions. Furthermore, it was challenging to decide upon the appropriate use of language within the videos. For example, knowing how to phrase things specifically for the context of the video, or, conveying information and meaning to an 'unknown' person. It was found that whilst the plwMND would have a firm

understanding of the young person during the time in which the digital legacy was recorded, they would not 'know' the young person as a future adolescent or adult, when the legacy may be accessed. The plwMND would therefore spend a great deal of time planning, preparing and rehearsing their responses. This further added to the time required to create their digital legacy, and additionally, could unintentionally create a 'sanitised' version of themselves (Tommy, Chapter 6, page 163). Interestingly, this contradicted with the 'warts and all' type of legacy that bereaved young people suggested that they would want (discussed in more detail later, page 266).

A final challenge for plwMND in creating a digital legacy was to retain a sense of motivation. As previously described, creating the digital legacy provided them with a sense of purpose and meaning to life. Yet, it was also quite overwhelming and emotional at times. This was due to the recording process acting as a constant reminder of their illness and imminent death. As suggested by John, recording his digital legacy was '*like bit of a slap in the face*' (Chapter 6, page 169) which could distract him from his wish to live in the moment. Understandably, the process of reflecting upon a past life before the disease, and also imagining their own absence in the young person's future, often made plwMND become quite emotional. This has similarly been noted in the existing literature regarding dignity therapy. Participants in a study conducted by Tait et al. (2011) described the challenge of shifting focus away from '*living one's life*', to reflecting and dwelling upon a life that '*had been lived*' (p.2). This clearly had a negative impact on motivation for plwMND to record the digital legacy due to an underlying wish to not '*leave any negativity as a legacy for my family and kids*' (Tommy, Chapter 6, page 168).

Of further pertinence was that engaging in a period of reflection could also evoke painful or challenging memories (Redhouse, 2014). For example, John described how he wanted to include biographical information about his experience of child abuse during his formative years (Chapter 6, page 147). This finding has also been outlined within the literature regarding life review for patients with a terminal illness, suggesting it to not be uncommon (Weishaar, 1999). However, whilst it was often challenging to revisit such painful memories, this may provide an opportunity and platform to reconcile unresolved issues from their past in light of their imminent death (Butler, 2002; Tait et al., 2011; Redhouse, 2014), thus promoting psychosocial wellbeing in plwMND reducing psychological distress (Averill, Kasarskis and Segerstrom, 2007).

An additional finding was that becoming overwhelmed was closely 'knitted' with an awareness that the disease was constantly progressing. As such, there was a conflict in wanting to fully utilise the windows of opportunity, whilst also being mindful of not becoming overwhelmed with the project (Allen, 2009). Becoming overwhelmed was not only attributable to being forced to think about their imminent death, but also that finishing the digital legacy was an unachievable task. In contrast with some of the existing literature regarding the creation of broader legacies (Ando et al., 2010; Houmann et al., 2014), this finding also suggests that creating a digital legacy may actually increase a sense of burden for some plwMND. Regardless of the source of becoming overwhelmed, it was highlighted that it could cause a type of burn-out for plwMND in creating their digital legacy. This has been similarly highlighted in

existing literature where interventions are carried out over an elongated period of time (Keall, Clayton and Butow, 2015). It has therefore been recognised that interventions which encourage people with a slower progressing terminal illness to reflect upon life, should be viewed from the offset as a long-term work in progress, rather than a quick task (McNees, 2009). The plwMND therefore developed coping strategies whereby they would have breaks from recording. This not only provided an opportunity to plan and prepare future recordings, but also gave them time to not be reminded of their illness, mortality, and lack of a future with the young people. This reinforces the need for discussions to take place early on the disease trajectory in order for plwMND to be provided with optimal end of life guidance and support (National Institute for Health and Care Excellence (NICE), 2016a; Oliver and Marsden, 2016).

## **9.2 - Writing the penultimate and last chapter (bereaved young people)**

The following section of the chapter will focus on the findings related to bereaved young people using a digital legacy. This will begin with a theoretical discussion which provides a new way to synthesise existing theories regarding the creation of 'penultimate' and 'last' chapters (Walter, 1996; Fearnley, 2015). It is argued that use of a digital legacy provides a new and novel way for young people to develop these chapters, in order to create their 'durable biography' (Walter, 1996). Following this, a more practical discussion will be directed towards the various benefits and challenges for bereaved young people using a digital legacy.



### 9.2.1 - Developing the last chapter and having an ongoing narrative

As inferred by the illustrated 'Model of Reciprocal Bonds Formation', the digital legacy has been 'knitted' into a 'garment' which is given to the bereaved young person upon the death of the plwMND. Similar to the scarf, the digital legacy will consist of a number of 'threads' that the plwMND has 'knitted' together to create their autobiographical chapter.

Like the scarf in the picture, the bereaved young person is able to isolate and identify the various 'threads' which comprise the digital legacy. It is then possible to extract knowledge, information and meaning from the digital legacy, which will contribute to the young person's writing of the last chapter and durable biography (Walter, 1996). Consequently, the presence of biographical information within the digital legacy was of importance for bereaved young people. It therefore became a vehicle which could provide the young person with '*a picture of what that person's life was like*' (Kacey, Chapter 8, page 230). Moreover, the digital legacy provided the young person with an opportunity to meet '*a person that [they] didn't know, just because [they didn't] remember it happening in the flesh*' (Sophie, Chapter 7, page 194). The findings from this study therefore support the idea that developing representations of the deceased is beneficial for bereaved young people, thus having a lasting impact upon developing their own autobiography and identity (Field, Gao and Paderna, 2005).

Additionally, however, it was found that plwMND also wanted to convey an 'illness related narrative' to the young person. For example, it was important for John to document the progression of the disease within his digital legacy for his son (Chapter 6, page 155). This resonates with the concept of developing a penultimate chapter (Fearnley, 2015). The young person would obtain additional knowledge about the plwMND's illness through accessing the digital legacy in the future. Based upon these findings, this suggests that the process of writing the penultimate chapter, and last chapter, may be somewhat iterative. A bereaved young person may use the digital legacy at a much later point in their life to acquire additional knowledge about the plwMND's life and illness. Therefore, the writing of the penultimate chapter, and ultimately their durable biography, could be carried out throughout the young person's life. This finding resonates with the continuing bonds model of grief, emphasising that bereavement is non-linear and potentially a life-long process (Silverman, Klass and Nickman, 1996; Packman et al., 2006).

Building upon this idea further, it was also found that the digital legacy provided bereaved young people with information about the plwMND's personality and identity. Often this was implicitly conveyed through the recorded mannerisms of the plwMND, or, by hearing the sound of their voice (Chapter 7, pages 188-192). As described by Sophie, who reflected on using the video legacy of her father, *'he wasn't saying anything in particular, he was just laughing and maybe calling one of our names'* (Chapter 7, page 189). Consequently, this *implicit* information provided additional *'pieces to the puzzle'* (Isabelle, Chapter 7,

page 190), which enabled further development of the durable biography, and an ability to intertwine particular aspects of the plwMND's identity into their own (Walter, 1996). The ability for bereaved young people to internalise cherished aspects of the deceased's personality and identity, has been suggested to be a crucial part of the grief journey allowing young people to perpetuate the memory of the deceased (Normand, Silverman and Nickman, 1996; Pearce, 2008; Wood et al., 2012).

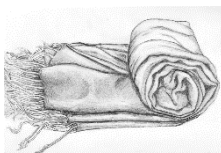
Of further interest, was that bereaved young people tended to want a holistic 'warts and all' overview of the plwMND. They described how they wanted to learn more about the personality and character of the person before the illness. In essence, they did not want a digital legacy where the plwMND's idiosyncrasies had been omitted. These characteristics were recognised by the young people to be crucial features of the personality and identity of the plwMND. As such, not including them within the digital legacy would create an inaccurate representation of the plwMND. Based upon findings from this study, bereaved young people would prefer a more naturalistic type of digital legacy. This finding reinforces existing literature which similarly highlights that bereaved young people seek a *balanced picture* of the deceased (Nickman, Silverman and Normand, 1998). Interestingly, however, this finding contrasts with the thoroughly prepared and well-rehearsed digital legacy that Tommy had created (Chapter 6, pages 163-164). It is therefore clear that a balance must be achieved between the digital legacy meeting the future needs of bereaved young people, whilst also being created in accordance with the plwMND's unique wishes and capabilities.

It was also found that the digital legacy supported bereaved young people by providing a type of evidence of the once-shared relationship with the plwMND. For the bereaved young people in this study, this again was implicitly conveyed due to the video legacy not being purposefully recorded. As described by Isabelle, her father '*wasn't speaking to the camera*', yet seeing him '*holding [her] and things like that*', reinforced a sense of the previous relationship (Chapter 7, page 193). This was important for the bereaved young people as they did not tend to have any recollection of this relationship and bond. The digital legacy therefore provided evidence that '*he did love you*' (Sophie, Chapter 7, page 194), which clearly was an important feature to be written into their last chapter. It provided a sense of comfort and security knowing that this relationship had once existed due to such memories not currently featuring within their durable biography. It was then possible to synthesise this new information into their existing knowledge regarding their father. In contrast, the digital legacies created by the plwMND provided *explicit* detail of the relationship and bond they shared with the young person. As these autobiographical chapters in the form of digital legacies were purposefully recorded, the plwMND made a point of clearly describing and talking about their relationship with their child. In recognition of 'The Model of Reciprocal Bonds Formation', it is argued that synthesising information from the person's autobiographical chapter (the digital legacy), into the young person's durable biography, becomes a more streamlined process.



A final way in which the digital legacy contributed to the development of a durable biography, was through reinforcement and modification of existing memories. This resonates with Walter's (1996) idea of the last chapter being written from information and stories provided by other survivors. In contrast, however, the digital legacy became a readily accessible repository of information which the young person could draw upon (Irwin, 2015). The findings from this study therefore suggest that the bereaved young person could reinforce knowledge of the plwMND through use of the digital legacy. For example, Isabelle described how the videos of her father validated memories of him before he become ill and was still able to walk (Chapter 7, page 187). Additionally, the digital legacy would also trigger memories of the plwMND in the same way that Walter (1996) suggests stories from other survivors provides. It is suggested that *'the more opportunities that are available for bereaved children to talk about and, importantly, hear stories about the deceased person, the more robust their biography about the person will be'* (Fearnley, 2015, p.166). However, a restriction of this is that young people require essential input from interested survivors to provide the stories that will evoke memories of the deceased (Christ, Siegel and Christ, 2002). This may not always be possible during the young person's life due to survivors being reluctant to talk about the deceased (Saldinger et al., 2004). It is therefore argued that a digital legacy creates an alternative, and readily accessible way, for bereaved young people to write their last chapter, and therefore create a durable biography.

Furthermore, use of a digital legacy could modify existing memories which featured heavily within the young person's penultimate chapter. Such memories are likely to be focused upon disease related symptomatology which would directly influence the young person's durable biography. Existing literature suggests that revisiting a parent's illness and death allows bereaved young people to reprocess their grief and loss (Biank and Werner-Lin, 2011). Consequently, using the digital legacy which has been recorded during the period of illness, could arguably amend the young person's penultimate chapter, thus positively reshaping their durable biography.



### 9.2.3 - Challenges and implications for bereaved young people using the digital legacy

Understandably, it was found that using a digital legacy would create a number of challenges for bereaved young people. It was necessary at times to put the digital legacy away, just as one would put a scarf away when it is not being used, in order to overcome these challenges.

The first of these challenges was regarding the timing in which the digital legacy was used by the young person. It was suggested that during the initial period of bereavement, immediately after the death, it was inappropriate to use the digital legacy. A period of adjustment was required where the young person could come to terms with the death, and overcome a sense of numbness that was experienced (Becky, Chapter 7, page 205). Similar to plwMND having optimal windows to *create* the digital legacy (pages 258-259), there were optimal windows for bereaved young people to *use* the digital legacy within their grief journey. It was found that premature use of the digital legacy could

act as a reminder of the young person's loss, rather than provide a sense of comfort. It was also suggested that this sense of loss would be further enhanced with a *purposeful* digital legacy, as the plwMND would be directly 'speaking' to the bereaved young person. As with the plwMND, there needed to be psychological window for young people to be able to accept the death. This has been documented within existing literature to be necessary before bereaved young people can begin to seek ways to remember the deceased (Field, Gao and Paderna, 2005). It was therefore clear that preliminary ground work needed to take place which could ensure that the young person had reached an appropriate place within their grief journey, where there was acceptance of the death of the plwMND (Normand, Silverman and Nickman, 1996; Root and Exline, 2014). Following this groundwork, it would then be possible to ascertain whether the young person was psychologically ready to 'revisit the plwMND', albeit in a previously recorded digital format. Consequently, withholding the digital legacy from the young person might be necessary in order to '*give that child room to grieve*' and prevent potential harm from premature use (Grace, Chapter 8, page 238). This would reduce the likelihood of the digital legacy becoming what Gibson (2004) defines as a 'melancholy object'; something which stimulates negative connotations of the deceased.

Interestingly, it was suggested from the interviews with bereaved young people that regardless of the passage of time, use of a digital legacy may always evoke an emotional reaction. Sophie described how she became quite emotional when watching the video of her father and hearing the sound of his

voice, some 15 years after his death. It is therefore suggested that additional groundwork might be necessary in regards to the young person hearing the plwMND's voice again. This auditory element of the digital legacy was considered to be the most emotionally evocative aspect of the recordings (Chapter 8, page 241), thus reinforcing findings from existing literature (Brewer and Sparkes, 2011). Yet, even though the videos reminded the young people of their loss and '*what [life] could have been like*' (Isabelle, Chapter 7, page 204), they also provided a sense of comfort by hearing their deceased parent's voice and 'bridging' a connection with them (Normand, Silverman and Nickman, 1996; Brewer and Sparkes, 2011).

Additionally, knowing that the digital legacy had been specifically recorded for the young person could also create a sense of pressure that it needed to be accessed, perhaps prematurely. As suggested by previous research, this study found that plwMND could provide instructions or guidance regarding use of the digital legacy by young people (Saldinger et al., 2004). Being made aware of the purpose and content before first accessing it, would allow the young person to rationalise when to use it. This would further provide the young people with a sense of control and independence with how and when they engage with their grief work (Wood et al., 2012).

Lastly, a challenge for bereaved young people using the digital legacy was identified with regards to the content of the recordings. As previously described, the digital legacy has scope to evoke disease related memories of

the plwMND. Whilst for some bereaved young people this would provide an opportunity to modify their penultimate chapter, for others this may act as a reminder of the illness. With it being acknowledged that the digital legacy provides an immortalised version of the plwMND, use of the recordings would reinforce and create memories built upon symptomatology. As suggested by Willow, watching the digital legacy might *'make it all flood back [... and] take them back to that time when it was a bad time for illness'* (Chapter 8, page 239). This could therefore create an undesirable and unintended representation of the plwMND. However, it has been reported in existing literature that bereaved young people actively seek good and bad memories in order to develop a holistic picture of the deceased (Foster et al., 2011; Wood et al., 2012). This would suggest that bereaved young people may benefit from exposure to illness related memories in order to assist with their writing of the penultimate chapter (Fearnley, 2015).



#### 9.2.4 - Benefits for bereaved young people using a digital legacy

It was clear from the findings of this study that, like the scarf, the digital legacy could provide a sense of comfort and warmth for bereaved young people. The digital legacy became a platform to intentionally remember the plwMND, and gain a sense of a continued bond with them. This resonates with existing literature which suggests that bereaved young people actively search for ways to remember and reconnect with the deceased during their grief journey (Field, Gao and Paderna, 2005; Packman

et al., 2006; Gibson, 2014). In accordance with 'The Model of Reciprocal Bonds Formation' developed from this study, it is suggested that the young person must first develop a robust, durable biography of the plwMND, before establishing a continued bond. Only after this, will use of the digital legacy provide a sense of comfort for the young people - once they have found '*an appropriate place for the dead in their emotional lives*' (Worden, 1991, p.16). It is during this later stage of the grief journey that stimulating existing features of the durable biography will endorse a sense of continued bonds for the young person. Yet it is also acknowledged that use of the legacy will slowly diminish over time as the young person gradually begins to accommodate their loss (Field, Gao and Pederna, 2005).

This theoretical concept was reinforced by the experiences provided by the bereaved young people who were interviewed (Chapter 7). The participants already possessed a stable understanding and existing knowledge of the plwMND which the video legacy could stimulate. For example, hearing her father's voice provided a sense of '*ah, that's who my dad is*' for Sophie (Chapter 7, page 188). The video legacy therefore became a platform to reinforce this memory and '*keep that thread*' between the young person and plwMND (Willow, Chapter 8, page 232). As such, although the plwMND may have been physically absent, they continued to exist through the young person's memory of them (Pennington, 2013; Root and Exline, 2014).

However, this idea is also applicable to bereaved young people who are perhaps watching a new component of the digital legacy for the first time. For example, John described how he wanted his digital legacy to be viewed as a way to provide *'Daddy's answer to that question'* (Chapter 6, page 152). In this case, it is clear that his son will not already 'know' the content of the video to reinforce his existing memories. Instead, his son will have developed a 'stable understanding' that the digital legacy can provide answers to questions he may require answers to. This highlights that instead of existing *memories* of the plwMND being reinforced, the digital legacy can answer future questions the young person might have resulting in a continuation of bonds, even though the plwMND is absent. This concept reinforces existing literature which suggests that bereaved young people will often 'listen' to a perceived response from the deceased to questions (Wood et al., 2012). In contrast, the digital legacy will negate the need for young people to anticipate a response, as the plwMND will have already recorded one.

Hearing the plwMND's voice was a central way in which the digital legacy enabled a continuation of bonds. However, sometimes hearing the voice came as quite a shock to the young person, as they did not remember what the plwMND had once sounded like. This was suggested by Rita, a child bereavement researcher, as being quite common due to memories of voice often being the first thing we forget when somebody dies (Chapter 8, page 228). Regardless of this, the recorded sound of the plwMND's voice within the digital legacy meant that it evoked special thoughts, feelings and memories for

the bereaved young person. In turn, this provided the young people with a sense of comfort and relief after *'want[ing] to hear his voice for so long'* (Sophie, Chapter 7, page 189). This was not always explicit vocal content, but simply hearing the plwMND laughing provided a sense of warmth and comfort for the young people.

Additionally, seeing the plwMND within the videos would also provide the young person with a sense of comfort. It was possible to reinforce cherished memories regarding the plwMND's physical appearance or mannerisms. Consequently, *'actually seeing them [...] brings back the memories'* (Grace, Chapter 8, page 228), something which has previously been mentioned in existing literature (Foster et al., 2011). Moreover, seeing them smile provided evidence that they were happy before they became ill, thus providing a balanced picture of the person's life (Brewer and Sparkes, 2011). This benefit of the digital legacy resonates with the continuing bonds model of grief (Silverman, Klass and Nickman, 1996). It is therefore argued that *'sight, sound, touch, taste and smell, individually or collectively, can act as a bridge in the continuity of relationships between the living and dead for parentally bereaved young people'* (Brewer and Sparkes, 2011, p.289).

As suggested by existing literature, and Jess (a child bereavement therapist), some young people would gain more comfort from hearing the plwMND's voice than seeing them (or vice-versa) (Simpkins and Myers-Coffman, 2017). Due to the digital legacy capturing both visual and audio elements, it would be possible to tailor exposure in accordance with the young person's unique



sense preferences (Brewer and Sparkes, 2011), by blocking either visual or auditory elements of the recording. This was regarded as an additional benefit of a digital legacy and would allow optimisation of bridging the gap between the plwMND and young person, providing comfort through continuing bonds. An additional benefit was that the digital legacy could be given to the young person as a tangible resource which would provide a sense of having '*something concrete that they can turn to*' (Pearl, Chapter 8, page 234). This may be particularly useful for younger children who potentially struggle with abstract concepts such as death due to their developmental understanding (Packman et al., 2006). A tangible resource would therefore allow the child to 'locate' the plwMND through use of the digital legacy, thus endorsing a continued bond.

Developing this further, the digital legacy would also provide a readily accessible way for the young person to connect with the plwMND when needed (Root and Exline, 2014). Existing literature suggests it to be common for bereaved young people to want to feel close and connected to the deceased (Field, Gao and Paderna, 2005). The presence of a digital legacy meant that the young person could '*keep that person in [their] life*' by accessing the recordings made by the plwMND (Kelly, Chapter 8, page 233). The fact that it was a digital resource meant it could be watched by the young person whenever they felt the need to be connected with the plwMND throughout their life (Biank and Werner-Lin, 2011). It was therefore clear that the digital legacy

would provide a valuable way for bereaved young people to '*go back to the memory*' shared with the plwMND (Foster et al., 2011, p.429).

It was also found that use of the digital legacy could provide the young person with an important sense of flexibility and control regarding their engagement with grief work (Irwin, 2015). All or part of the digital legacy could be transferred to a mobile device to be carried around with the young person, thus breaking it down into 'small chunks' (Packman et al., 2006; Fearnley, 2015). Furthermore, this flexibility means that the young person would not be forced into remembering the plwMND when they did not feel it appropriate or necessary. This is of pertinence as it is not uncommon for dying people to leave birthday cards and gifts for young people to receive at key stages in their lives. Whilst this is often planned with good intentions by the person who is dying, it can force the bereaved young person to have to remember the deceased and be reminded of their loss at moments in their lives when they would normally be celebrating (Silverman et al., 2002; Saldinger et al., 2004). In contrast, a digital legacy would ensure that remembering the person, and having that continuing bond, would only occur when initiated by the young person themselves (Root and Exline, 2014). This resonates with Stroebe and Schut's 'dual process model' of grief (1999) whereby the bereaved oscillate between loss and restorative orientations. The digital legacy would therefore provide a readily accessible way to engage with loss orientation tasks and offer a method for the young person to '*self-soothe*' (Kelly, Chapter 8, page 236).

### **9.3 - Summary and original contributions to knowledge**

This discussion chapter has provided a summary of the key findings from the study in relation to existing literature. As noted in Chapter 1, the overall aim of the study was to investigate the experiences, views and perceptions of digital legacies with people affected by MND. Through conducting in-depth interviews with plwMND, bereaved young people and healthcare professionals, specialists and experts, it is argued that the findings from this study have helped to address the gap in current understanding. With this in mind, the study objectives outlined in Chapter 1 have been achieved.

It should be acknowledged that the concept of digital legacies is still in its infancy, with specific relevance to plwMND currently being non-existent. To date, this is the first IPA study to investigate the use of digital legacies with people affected by MND from these three distinct participant lenses. As the existing literature regarding this topic is currently somewhat limited, it was necessary to adopt a relatively interpretative approach to extrapolate related issues. This has meant that findings from the study provide a valuable contribution to an emerging body of knowledge.

Finally, the development of 'The Model of Reciprocal Bonds Formation', which has been introduced within this thesis, provides a conceptual original contribution to knowledge. An important element of the model is the new

concept of an 'autobiographical chapter', in addition to the application of certain 'windows of opportunity'. Both of which add new elements to the existing literature and create an extended holistic model. Based upon findings from the study, it is argued that a digital legacy provides mutual benefits for both plwMND who create it, and bereaved young people who use it. Due to the broad and versatile nature of the model, there is clear scope for its transference to other non-MND populations (e.g. Huntington's, cancer or dementia), thus contributing to the broader existing knowledge regarding the provision of optimal support for carers, the bereaved, and people living with a terminal illness.

In accordance with IPA research, the next chapter will focus upon personal reflections from conducting the study followed by the concluding chapter which assesses the strengths and limitations of this study before providing recommendations for future practice, policy and research.

## Chapter 10 - Reflection

“There are three methods to gaining wisdom. The first is reflection, which is the highest. The second is limitation, which is the easiest. The third is experience, which is the bitterest.”

Confucius (551-479 BC)

In this chapter I will provide a brief rationale for creating a reflexive diary whilst conducting this IPA study. In accordance with the hermeneutic approach underpinning IPA, I will then reflect upon my own personal experience during a selection of key moments that occurred during the study. Each of these moments were documented in my reflexive diary written at various occasions throughout the duration of the study. These extracts, as suggested by Smith, Flowers and Larkin (2009), exemplify specific moments throughout the study which became significant experiences for me as the researcher.

### 10.1 - Rationale for creating a reflexive diary

It has been suggested that use of a reflexive field diary not only enhances rigour in qualitative research, through creating an audit trail (Koch, 1994), but can also help researchers develop their understanding and insight towards the research topic (Clarke, 2009b). Discussed in his book ‘A View from Nowhere’, Nagel (1986) outlines that each of us has a unique and personal view on the world and the specific phenomenon we are considering. As described in the methodology (Chapter 4), Heidegger (1962) suggests that whilst we all share

some mutual understanding of the phenomenon (Mitsein), as individuals, we also possess unique thoughts and ideas (Daesin). It was therefore necessary to engage in a process of reflection upon my own personal history and experiences, in order to ascertain how this influenced and shaped the study (Eatough, 2012). Often research is implicitly influenced by the researcher's background, values and beliefs throughout the development and conducting of the study (Willig, 2013). This is particularly notable in IPA during the process of data analysis whereby interpretation of participant data is shaped by the researchers '*experientially-informed lens*' (Smith, Flowers and Larkin, 2009, p.36). As described in the preface of this thesis, I have personal experience regarding MND, which not only shaped the development of the study, but also provided the basis of this lens used during the analysis of data.

IPA researchers therefore acknowledge and reflect upon their unique thoughts and feelings throughout the research journey (Biggerstaff and Thompson, 2008). This is often a dynamic process which implicitly occurs. However, the action of writing a reflexive diary enables an explicit process of clarifying ideas, beliefs and feelings which further enhances critical thinking (Jasper, 2005). It then becomes possible for the researcher to begin to comprehend and differentiate between experiences which are unique, and those which are shared. This endorses the researcher to suspend their unique judgments and beliefs about the phenomenon, and instead, create '*a co-construction between participant and analyst*' of the research phenomenon (Osborn and Smith, 1998, p.67).

## 10.2 - Reflexive discussion

I began my own reflexive diary as soon as I embarked upon my PhD journey. Having never kept a diary in the past, I initially saw this as a fruitless task which had simply been prescribed by IPA literature. However, I decided to oblige as the large number of researchers who had written about the importance of keeping a reflexive diary, possessed significantly more IPA research experience than I did. Like Clarke (2009b), my early diary entries were no more than a list of memos, ramblings and tasks to be achieved that day, week, month. Looking back at these early entries now, it seems ironic that my *reflexive* diary contained *no reflection*, merely a list of short bullet point sentences. Yet, as my own journey developed as a researcher, so did the depth and reflection of my diary. As suggested by Smith, Flowers and Larkin (2009, p.33):

*'With IPA, we are concerned with where ordinary everyday experience becomes 'an experience' of importance as the person reflects on the significance of what has happened and engages in considerable 'hot cognition' in trying to make sense of it.'*

Throughout the study, I had focussed upon the significant experiences described by each of the participants. Unbeknown to me, my reflexive diary had captured various moments, throughout the study, which were of significance for me. Interestingly, the diary became a place where I not only documented mundane daily tasks and activities but, when required, also provided a safe space for my *'hot cognition'*, somewhere for me to vent and express my inner thoughts, feelings, and personal emotional challenges. As such, four extracts from my reflexive diary have been provided below. These particular diary entries were identified as memorable and significant moments that I had experienced throughout the duration of the study whereby I *'engaged*

*in considerable 'hot cognition' in trying to make sense of it' (Smith, Flowers and Larkin, 2009, p.33).*

Like Hanley (2013), my aim in interpreting these specific diary entries is not to highlight my biases and subjectivity. Instead, I recognise that my personal background, knowledge, thoughts and feelings, are assets used to support my interpretation of participant experiences. Therefore, the aim of this chapter is to highlight the reciprocity of these specific experiences. Whilst my own personal background and idiosyncrasies have shaped the research and interpretation of these four events, it is also clear that these experiences provided a platform for my own personal development as an IPA researcher (Willig, 2013).

#### *Diary extract 1: an online forum response*

This first diary extract (in italics) was written following a response I received to a recruitment post which I had published on an online forum. An anonymised copy of the forum discussion is provided below (Figure 17) to offer contextualisation for my diary excerpt.

*Friday 11<sup>th</sup> December*

*This afternoon has not been good! I've had a response to one of the recruitment posts I put on a forum... not a good response! I feel so angry and upset. He just doesn't 'get' my study at all. What's really pissed me off is that he is suggesting that 'my idea borders on being a little sick'. Posts from other people have been really supportive, but his is really shitting all over me and my research! I'm not entirely sure what to respond with, or even if I should! I know I should probably wait until I've calmed down so will at least leave it until tomorrow. It does make me wonder whether he's right though? Is this why I've not got any new participants? Is it because the whole idea of created a D/L is 'sick'?*



Figure 17- A copy of the forum discussion

Rank:

Groups:

Joined:

Posts:

Posted: Wednesday, December 09, 2015 4:21:48

I doubt you'll get any takers. To me, ALS is a private matter, to be shared with family. Last thing I'd want to do is have u interview me. Sorry for your mom and dad.

Diagnosed by

- 13 yrs Symptomatic since 2003

olly2015  
(/forum/yaf\_profile51326.aspx)

Rank: Newbie

Groups: Member

Joined: 9/30/20 15

Posts: 3

Posted: Friday, December 11, 2015 2:42:43 PM

Hi [REDACTED] and [REDACTED]-thanks for your replies

[REDACTED] - I completely understand that ALS is a private matter, especially the personal messages for children. I'm not wanting to know what the messages are about/consist of. I'm looking at the experience of creating and/or using a video based digital legacy. Beyond my study (and on a much more personal level) i hope to raise awareness of digital legacies for people affected by ALS.

Rank:

Groups:

Joined:

Posts:

Posted: Friday, December 11, 2015 2:53:39 PM

Why would people with ALS want to make a digital legacy of them slowly succumbing to the disease?  
Think about it as if it was yourself. Would u want your family to slowly watch you go from being a man to a invalid? All on a disk for the, to watch over and over?  
I think u may have good intentions, but your idea borders being a little sick.  
U can see what people think of your idea by the amount of post . I'm just a outspoken prick that has a very strong opinion on watching families of people with ALS slowly become a shell of what they used to be.

Diagnosed by

- 13 yrs Symptomatic since 2003

Rereading this post from the forum user, I can still resonate with the frustration and anger that features in my diary entry. Seemingly, much of my frustration is attributable to the forum user's misunderstanding of the purpose and aim of creating a digital legacy. The forum user seems to believe that creating the videos are to provide a type of 'running progression' of a plwMND's decline. In hindsight, I believe my frustration originates from the user misunderstanding the aim and purpose of the study. It therefore raises questions whether my briefing information for online forum posts was comprehensive enough to avoid confusion.

It is also quite clear from the diary extract that I take exception to my '*idea bordering on a little sick*'. I assume that this resentment to his comment originates from my own personal experience of finding comfort from using a 'digital' recording in the form of the answerphone message created by my Dad. Yet, upon reflection, I would also hasten to add that some of my anger may be due to an element of empathising with him. As with much of my research journey, recruitment of participants was extremely challenging. At the point in time when this forum post was made, I had not received any interest from participants for some time. I therefore wonder whether the accusation of my study '*bordering on a little sick*', stimulated existing doubts in my own mind? Was this the reason I had so few willing participants? Interestingly, I mention that '*other people have been really supportive*', which suggests that I needed verification from others regarding the worthiness and value of the study.

A final point to explore from my diary entry is the perception that the forum user's post is '*really shitting all over me and my research*'. Clearly I was not referring to the user actually defecating on me, the study, or study materials. This was an interesting choice of metaphor to describe how I felt in reaction to his response on the forum. The use of profanities is not common place for me, however, it does infer a sense of feeling hurt or taking exception to his unique perception of the study. I recall a sense of fear that other forum users would read this response from him and similarly decide that the study was 'sick', potentially changing their own perceptions and willingness to participate. There is also an inference of the study almost being an extension of myself, and vice-versa. Therefore, I perceive critical feedback and negative opinions of the study as being synonymous and reflective of myself as a person, and, an IPA researcher. After dwelling upon this reflection further, does not come as a complete shock or surprise. The study originates from my personal experience which suggests that the experience of conducting the research was always going to be somewhat emotionally charged. Yet, I seemingly find it challenging to draw a distinction between '*what is me*', and '*what is the study*'.

This resonates with the Heideggerian (1962) concept of Dasein, questioning what it means 'to be' in the world. In this context, however, I am not questioning my own physical Dasein, but the extension of self that I have developed in the form of the study. Moreover, it is clear that while the forum user and I share a Mitsein with common knowledge and experience of MND, our Dasein is unique. As exemplified by the forum user, not all plwMND possess the same

attitudes and beliefs towards digital legacies. This may seem like quite a naïve realisation, however, prior to receiving negative feedback about digital legacies, I had assumed that everyone perceived it to be positive and beneficial. This forum post therefore opened my eyes to acknowledge that creating a digital legacy is not something that is appropriate for *all* plwMND. Moreover, this experience enabled me to hone key skills as a researcher by upholding personal integrity, whilst remaining professional in a somewhat challenging situation.

*Diary extract 2: MND Association branch meeting*

The second extract was written shortly after a presentation at a local MND Association branch meeting in an effort to raise awareness and recruit participants. While the beginning of the extract reflects upon the content and delivery of the presentation, the following section describes an emotional interaction with a member of the branch.

*Wednesday 13<sup>th</sup> January 2016*

*[...] I then went and sat down and straight away a lady came over and sat next to me. Instantly, she said “now I'm going to cry but I need to talk to you about this”. She told me that she was recently going through her phone and came across a video of her husband where he was talking. She then said that he had lost his voice now, and as she said that, started to cry. Bit of an awkward moment as she was crying and just saying “so if you give me one of the information sheets”. I touched her arm and felt reluctant to just pull out an information sheet whilst she was crying as that would seem a bit like- “I don't care about your problems, here's the info about my study, take it!”. So I carried on talking to her. I didn't quite know what to say so said about making sure the video was backed up, and asked about her grandchildren. Her husband was at the group too, but was chatting to another gentleman. She sat with her back to him, I guess so he couldn't see her crying?*

What strikes me the most about this extract, is the lady providing anecdotal evidence of how much she values the video of her husband and the recorded sound of his voice. Clearly *watching* the video is highly emotive, but judging by her warning as she sits down, she is aware that simply *thinking* about the recorded video evokes emotions too. It is also interesting that I mention her sitting with her back towards her husband, seemingly to prevent him seeing her become upset. I have since reflected upon this and wonder whether she had talked to her husband about the video that she had discovered on her phone. I also wonder whether she didn't want her husband to see her crying about the loss of his voice, as he will similarly be upset and angry about not being able to speak too.

There is also a sense of awkwardness in this extract regarding my reaction to her being upset and crying. I have always been proud of my empathic abilities and would say that this is evidenced within the diary extract. The sense of awkwardness during this interaction therefore stems from the dichotomy between wanting to help and provide comfort, whilst also being aware of my role as researcher. I am reminded of various lectures as an undergraduate student on qualitative research methods, and sessions on ethics as part of my PhD training. It was frequently emphasised that a researcher has a specific role whereby the study is priority, and '*you are present as a researcher, not a friend*'. However, this concept somewhat contradicts the ethical principle of non-maleficence whereby we, as researchers, do no harm (Beauchamp and

Childress, 2012). It is clear from this diary extract that simply talking about the study had caused an element of harm which caused the lady to become upset. Accordingly, it was my responsibility as a researcher to rectify this as best as I could. Clearly the lady could exercise her right to terminate this interaction at any point by simply walking away from me. However, she remained with me and continued to talk about the video of her husband, inferring a sense of ongoing and informed consent.

I would argue that my feeling of discomfort in this scenario is based upon a personal perception of '*what a researcher should be*'. Should I have simply disseminated information about the study to the lady who was requesting it? Or, honour my core values and provide comfort to someone who is upset? I would argue that I reacted in a balanced way whereby I first provided emotional support and comforted the lady. In accordance with ethical codes of practice, study information was then only offered to the lady once I had deemed it appropriate and acceptable (Beauchamp and Childress, 2013). It became clear that I had ensured that the lady's emotional wellbeing had priority over the study.

This experience also made me realise that ethical principles such as non-maleficence, are not static concepts which only require consideration during the creation of a research proposal or periods of data collection. As exemplified in this scenario, 'doing no harm' is something which spanned the whole

research process, including the recruitment of participants. I therefore adopted an awareness during future presentations with potential participants, to be wary of people becoming upset. Whilst this did not happen to the same extent again, I did make a point of informing potential participants of the service support sheet included within the study information pack when handing them to people. This ensured an awareness that further support was available to them, if required, whilst also adhering to ethical approvals.

Diary extract 3: interview with Charlie

This extract was written a few days after interviewing Charlie in his home. It was a particularly challenging interview as Charlie and his wife discussed at some length the death of their daughter two years before I had met them. Unsurprisingly, this evoked a great deal of emotion for them both. Surprisingly for me, however, the interview had a strong emotional impact on myself when I returned back to the University.

*Thursday 28th July 2016 (interview was on Monday)*

*[...] The interview came to a close and I left with both Charlie and his wife in an okay place (i.e. Not crying). I drove back to Uni and didn't think too much/process the interview. I came to debrief with Mary [supervisor] and although I mentioned the crying [Charlie/wife], I focussed more upon the factual details of Charlie's digital legacy. Unbeknown to the reasons why, I didn't feel too great that evening. I tried to figure out why I felt so low and couldn't put my finger on it. Charlie wasn't a father to young children like some of the other people I have spoken too? I put it down simply to the fact that Charlie and his wife had both got upset and had cried.*

*The next day I decided to transcribe the interview whilst it was still fresh, and, to not have it looming over me. I spent the day doing it*

*and realised that whilst I was listening to it, writing it, processing it, things were very raw. Some of the emotions came across a lot stronger from Charlie and his wife when re-listening. I got to within 15 minutes of the end of the recording and wanted to stop, but decided to carry on so that it was finished and a 'job done'. All the time, I was getting more and more agitated, angry and frustrated (later note: stress ball actually became 'balls' after ripping it apart!) I thought this was simply because I had been at the computer and on my own in the office all day. In hindsight, it could have been emotions?*

*Barbara [supervisor] came in late afternoon/evening just before I was going to go home and asked how I was. I said that I felt low for some reason. Couldn't put my finger on it. That night, I still felt rubbish, but didn't know why. I ended up doing lots of things to keep busy- but not consciously. Took my phone to bits, cleaned my room etc.*

*Supervision yesterday, it was mentioned and I could feel myself getting teary and red in the face. Kate [supervisor] mentioned that it can sometimes not be what people are discussing that can evoke emotions in other people, but simply, the understanding of that same emotion. In this case, grief and bereavement and it still being so raw.*

*Decided to have a couple days off from MND/PhD and made a mental note to become aware of this 'feeling' in the future. Distance, time apart and processing is essential for my own well-being.*

I remember this interview very clearly, and rereading this diary entry, takes me straight back to speaking with Charlie at the side of his bed. Both Charlie and his wife were incredibly welcoming and friendly when I arrived at their home. His wife answered the door and straight away supplied me with chocolate biscuits and Charlie's signature drink (coffee with condensed milk). Both of which, I am extremely accepting of.



Of pertinence in this diary extract is my adverse reaction to the interview, something I have since recognised as being the after-effect of an interview. At the time, I had no idea why I was feeling the way I was. I knew that I felt low, frustrated and irritable, but struggled to pinpoint the reasons why. Finding activities to distract myself and then feeling low and irritable, suggests some unconscious resonance had occurred during the interview. I seemingly hypothesise reasons why I shouldn't have felt the way I did and offer explanations for my reaction: "*Charlie didn't have young children*", "*the process of transcribing*", "*the irritability was due to working alone in the office*". Regardless of the potential explanations, it wasn't until I discussed the issue during my supervision that it became clear that there was not a *singular* reason for my reaction. Simply, the discussion of loss and bereavement, and moreover, witnessing Charlie and his wife's emotional reaction, triggered similar thoughts and feelings within myself. It made me remember the period following my Dad's death which unexpectedly brought back feelings which I had not experienced for a number of years. Similar to the previous diary extract (number 2), it was my empathic attitude which influenced my reaction to the interview and triggered a personal emotional response to past events in my life.

Following this interview, I became aware of the importance in ensuring my own mental wellbeing before undertaking study related tasks due to the personal closeness of the research topic. For future participants, I made sure that I left an adequate period of time between conducting the interview, transcribing, and later analysis of data.

More importantly, however, this experience made me realise the benefit of remaining transparent with my supervisory team. I was initially reluctant about telling more experienced and established researchers about how I was feeling in fear of seeming incapable of conducting the research. In reality, I obtained a sense of comfort and relief through expressing myself which ensured that I gained appropriate and necessary emotional support and guidance.

Upon reflection, I think part of my adverse reaction may be partly associated to the sudden shift of emotions during the interview. It began with Charlie and his wife being somewhat upbeat and very matter of fact about his illness and digital legacy. Yet, it suddenly became very emotional as the conversation evolved and they discussed the death of their daughter. This came as quite a surprise for myself. I had mentally prepared myself to talk with Charlie about MND, his digital legacy, and his own death. However, I had not contemplated the idea of discussing the death of their daughter and the associated emotions and pain. It therefore came as quite a shock to witness so much hurt and pain about something not related to MND. It has since made me aware that while interviews are conducted for a specific research topic, the nature of IPA research means that what participants choose to discuss, is far from predictable. However, it is also clear that this one of the strengths of open questioning within qualitative research as it provides an opportunity for participants to discuss what is important to them (Smith, Flowers and Larkin, 2009). An additional consideration is the need to plan appropriate support and debriefing for the researcher when conducting sensitive research. It is clear from this diary extract that I experienced a somewhat unexpected reaction to

the interview with Charlie and his wife. Yet, having a debrief with a member of my supervisory team following each interview was extremely beneficial for my own mental wellbeing. This is in keeping with Beauchamp and Childress's (2012) principle of protecting researchers from harm. Unbeknown to me, the harm had occurred during the interview with Charlie, yet didn't manifest until I had returned to the University. Thankfully, having accessible and empathetic support from my supervisory team alleviated this potential harm and made me recognise the importance of having open and honest communication with my colleagues.

Diary extract 4: interview with Isabelle

The final entry taken from my reflexive diary was written following the interview with Isabelle, a bereaved young person. As described in the diary extract below, the interview was quite emotional with Isabelle becoming upset and tearful a number of times.

*Wednesday 26 July 2017*

*I've just come out from speaking to Isabelle about her experience of losing her dad to MND and her use of videos since he has died. There were tears, which is awkward, as I know that she wouldn't have got upset this afternoon if she hadn't given up her time to come and speak to me. There is maybe a sense of guilt that I've caused this upset and her tears through her participation? I guess putting it into perspective, however, the upset is more a result of her bereavement and sadness related to her dad.*

*[...] The interview was challenging... for me. She was a similar age to me when her Dad was ill and died, meaning she is now the same sort of age as me. We talked about different times throughout our lives where we really wished to know more about our Dads. We talked about different times which have been hard for us. We talked about what we found hard, challenging and emotionally evocative about MND and bereavement.*

*Strangely, there was no awkwardness between us- even though there were tears and it was emotional. Instead, I felt a sense of comfort and contentment to be chatting to someone who 100% 'gets it'. We have the same life experiences and seemingly share views of what it is like to lose our Dads to MND. Moreover, there were significant parallels with our Dads' digital legacy. Whilst mine is an answerphone audio recording, hers is an old wedding video that was found by a family member which they did not know existed. We talked about how the digital legacy (whilst not too in-depth or lengthy in duration) provided a way to see/hear/understand how her dad interacted and behaved. That's the bit which I think is crucial.*

*[...] Regardless of the emotion throughout, the interview was really informative, and I got the impression that whilst she was clearly upset throughout, she didn't leave distraught. I walked her to the front of the building and thanked her extensively for her time. It is strange to meet someone in the 'MND dead dad club', but strangely comforting too.*

It is unsurprising that Isabelle's emotional reaction was an important and memorable feature of the interview. Within the first paragraph, I describe a sense of awkwardness and guilt that I caused this upset through her participation in the study. I have since reflected upon this feeling in the months after writing the diary entry, and still believe that part of this guilt is justifiable. It is unlikely that Isabelle would have become upset and spent so much time thinking about her Dad that afternoon if she hadn't of participated in the study. However, after transcribing the interview and analysing the data, I have since realised that participation in the study may have been quite cathartic for Isabelle. This is seemingly not an uncommon benefit for people who are bereaved that participate in research with it providing an opportunity to talk openly about the deceased (Germain, Mayland and Jack, 2016). It also suggests that people may participate in research for a variety of reasons, thus providing a plethora of benefits depending on their unique justification for taking part.

The day after interviewing Isabelle, I sent a brief email to reiterate my thanks for her time and participation. She sent a brief reply in which she said that '*it was nice to sit and talk openly about things I don't usually talk about*'. As such, the interview was a cathartic opportunity to reflect upon her Dad and provided a safe space to express emotions with someone who shares extremely similar life experiences (Germain, Mayland and Jack, 2016).

Interestingly, I then describe the challenges which I encountered during the interview. Much of the hardship was for the realisation that we shared such similar life experiences. I remember smiling on a number of occasions throughout the interview, and explaining to Isabelle that this was due to my resonance with what she was saying. This contradicts the perception that qualitative researchers '*generally do not divulge personal information about themselves during data collection*' (Ritchie and Lewis, 2004, p.20). In contrast, I found that the reciprocal sharing of thoughts, feelings and personal experiences, to not only assist in building rapport with participants, but to also promote a conversational feel for the interview (Zink et al., 2016). It is therefore clear that using IPA as the underpinning methodology for this study was advantageous as it enabled me to utilise my past experiences, rather than bracket them (Smith, Flowers and Larkin, 2009). Arguably, this aided more in-depth and rich descriptions from the participants as there was an underlying level of trust and knowledge regarding our shared experiences. However, it should also be noted that excessive self-disclosure from a novice IPA

researcher could be ineffective. This could draw the focus away from the participant, and create an interview whereby the researcher is essentially talking about themselves and their own experiences, rather than the participant's. It is therefore necessary to achieve a delicate balance whereby describing personal experiences will enhance the interview, rather than potentially over-power and distort the participant's unique perceptions. As suggested by Smith and Osborn (2007), this is a skill which needs to be honed in order to conduct a successful IPA interview.

As described in the diary entry, I found it comforting to have many thoughts and feelings validated by someone else from the 'MND dead dad club'. With this in mind, the dynamic of the interview was conversational and very much a co-construction of experiences (Smith, Flowers and Larkin, 2009). It became evident to me after transcribing and analysing this interview, that a real strength of my IPA interviewing skills, is the ability to have a '*conversation with a purpose*' (ibid, p.57). I began to look at interview transcripts from other participants. I found it comforting to identify this skill across the whole dataset, not only restricted to Isabelle. This reinforced a sense of competency with my interviewing skills which are crucial for IPA research meaning that my personal experiences and history were used to enhance the interviews I conducted (Smith and Eatough, 2012). I realised that I had interviewed a large number of participants, from drastically different backgrounds possessing highly varied

lived experiences. Whilst interviews with plwMND and bereaved young people required sensitivity and emotional intelligence, interviews with healthcare professionals required a more dynamic approach. Often these were much shorter in duration which required my interviewing technique to be more concise. Regardless of the participant population, the conversation throughout the interviews should always be free flowing and organic. This is something that I attribute to my interpersonal skills and have developed throughout conducting the research. As outlined in the email from Isabelle '*it helps that [I am] easy to talk to*' which has been crucial for conducting this study.

### **10.3 - Summary**

In this chapter I have engaged in a process of reflection based upon specific experiences that have occurred throughout my research journey. I have attempted to describe and interpret the thoughts, feelings and beliefs which I experienced during the various events stipulated in the diary extracts. It is clear that at times I have struggled with my role due to my personal background and close connection to the research topic. However, upon reflection and interpretation of these experiences, it is clear that elements of each event have been pivotal in developing my identity and skills as an IPA researcher. The following chapter will outline strengths and limitations of the study, before providing overall research conclusions and recommendations for future policy, practice and research.

## Chapter 11 – Strengths, limitations and recommendations

“The measure of greatness in a scientific idea is the extent to which it stimulates thought and opens up new lines of research.”

Paul A.M. Dirac (1902-1984)

The purpose of this concluding chapter is to highlight the various strengths and limitations of the study. The final section will outline the original contributions to knowledge that have been found from the study with application to future practice, policy and research.

### 11.0 - Strengths and limitations

There are a number of frameworks which enable the assessment of validity and reliability within qualitative research. As suggested by Smith, Flowers and Larkin (2009), one particularly useful checklist to assess the quality of IPA research has been provided by Yardley (2008). This describes the need to consider four key principles within the study- *sensitivity to context; commitment and rigour; transparency and coherence; and, impact and importance*. Each of these principles will now be discussed in turn with additional reference to the assessment of quality for IPA research (Smith, 2011), and consolidated criteria for reporting qualitative research (COREQ) (Tong, Sainsbury and Craig, 2007). A full copy of the COREQ is provided in the appendix for further reference to the quality regarding this study (see appendix 19).



### 11.0.1 - Sensitivity to context

As described by Yardley (2008), demonstrating a sensitivity to the research occurred early on in the research process. Firstly, I conducted a review of theoretical literature which provided the foundations for the conceptual framework developed from the study. An additional review of empirical literature was also conducted which similarly informed the design of the study. It was clear from this preliminary assessment of the literature that the use of digital legacies with people affected by MND had yet to be investigated. The existing literature regarding broader use of legacies had predominantly adopted qualitative approaches to the research (Chapter 2), thus emphasising its appropriateness for the current study. The design of the study was similarly informed by acknowledgement of MND being considered a 'rare' disease with a relatively low global incidence. With there being approximately 5000 plwMND in the UK at any one time (MND Association, 2017a), and the majority being aged between 55-70 years old (Hobson et al., 2016), an extremely modest number of potential participants was anticipated. Therefore, it would not have been possible to recruit an extensive sample of plwMND who had young people in their family, let alone the experience of creating a digital legacy for a young person. This meant that it was necessary to adopt a methodology, such as IPA, which emphasised a suitably idiographic approach (Smith, Flowers and Larkin, 2009). It is clear from the small, yet purposefully recruited samples of plwMND and bereaved young people, that this was achieved within the study.

In contrast, it could be argued that the larger sample of healthcare professionals, specialists and experts, does not align with the idiographic nature of IPA as a methodology. However, as outlined in Table 7 in Chapter 8, this larger sample comprised of smaller groups of specialists which provided the '*fairly homogenous sample*' required for IPA (Smith and Osborn, 2007, p.56).

A sensitivity to the context of the research was also demonstrated throughout the data collection process. As suggested by Yardley (2008), displaying empathy, overcoming interactional difficulties, and making participants feel comfortable during the interviews was necessary. As evidenced within the reflexive chapter (Chapter 10), and from communication received from participants after the interview, I would argue that this was well achieved in the study. Participants sent thank you messages, after their interview, for the opportunity to speak about their experiences, and some also described their involvement in the study to be cathartic. I believe that being empathetic and creating an atmosphere of comfort, were fundamental to gaining the rich and in-depth data described throughout the findings chapters of this thesis (Chapters 6-8).

Furthermore, sensitivity to the context of the study was achieved throughout the process of data analysis. As suggested by Smith, Flowers and Larkin (2009), this requires disciplined and extensive immersion within the data to ensure that the participants' accounts are fully understood and comprehended.

As outlined in the methods chapter (Chapter 5), the process of data analysis was long and multi-faceted. However, the resultant findings which demonstrate that I became fully immersed within the data and made '*sense of how the participant is making sense of their experience*' (Smith, Flowers and Larkin, 2009, p.180). Whilst challenging, this 'sense making' is fundamental to IPA research and therefore required additional sensitivity regarding the selection of appropriate verbatim quotes within the findings chapters (Chapters 6-8). In accordance with the idiographic nature of IPA, there was a desire to present extensive quotes from *all* participants in order to provide idiographic equity for each person's unique perspective and experience. However, in order to make this thesis accessible, and to keep the reader engaged, salient quotes were identified which best reflected the findings presented (Smith, Flowers and Larkin, 2009).

#### 11.0.2 - Commitment and rigour

Exemplifying a commitment to the research is also suggested by Yardley (2008) to gauge the quality of qualitative studies. This is firstly evident from a personal stance due to clearly demonstrating a long-standing commitment to the study throughout the duration of my PhD. However, my commitment to the topic is further evident from my personal experience of MND, as documented in the preface and reflexive chapter of this thesis (Chapter 10). This resonates with the COREQ which similarly outlines the importance of researchers documenting their reasons and interests for pursuing the research topic (Tong, Sainsbury and Craig, 2007) (see appendix 19). My personal commitment to the IPA methodology is also notable within the study. It was clear that

approaching the study as a novice researcher, I lacked skills in conducting IPA research. However, through attending specific IPA training sessions and by conducting the research, I have exemplified a commitment to, in Tommy's words (Chapter 6, page 176), '*better myself*' and become the developing IPA researcher that I now am.

It is also suggested by Yardley (2008) that rigour should be acknowledged as a marker of quality for qualitative research. This requires consideration of the 'thoroughness' in conducting the research (Smith, Flowers and Larkin, 2009; p.181). It is therefore argued that rigour was upheld throughout the study. Firstly, each participant was purposively recruited due to possessing a perspective, or experience, regarding MND, child bereavement, and digital legacies. This provided a homogenous sample which is required for IPA research. Of course, a potential limitation is the slight variation between each participant experiences. For example, each of the plwMND had created a digital legacy in different formats which may have influenced their perception and experience (e.g. Charlie had recorded a story while Tommy had recorded a type of biography). Additionally, the healthcare professionals themselves were not living with MND and had consequently not created a digital legacy for a young person within their own family. It is therefore hard to ascertain the validity of their perceptions regarding plwMND creating a digital legacy as they did not possess the same life experiences.

An alternative limitation of the study is that participants self-selected through initiating contact to express their interest in taking part in the study. It could therefore be suggested that plwMND who were willing to participate in the

study were potentially coping well their illness. As such, they may not be representative of other people with MND who did not come forward. However, in accordance with IPA principles, the conclusions from the study are not intended to be generalised to *all* plwMND or bereaved young people. As such, they provide a comprehensive understanding of '*what it was like*' for the unique sample of participants interviewed and those who have been affected by MND and created or used a digital legacy (Smith and Osborn, 2007, p.53).

Another perspective is that this method of recruitment offered an additional strength to the study. Through self-selection it was possible to recruit people from a wide geographical area. This arguably enhanced the representativeness of findings, whilst also providing participants with a sense of control and autonomy regarding their participation.

As suggested by Smith, Flowers and Larkin (2009), rigour was further enhanced during the interview process with careful use of prompts and probes, thus enabling me to '*dig deeper*' (p.181). Examples of these probes were provided in Chapter 5 to provide an additional level of clarity (page 120). After analysing data, it was necessary to present findings in a transparent way whilst ensuring an appropriate level of interpretation (Smith, Flowers and Larkin, 2009). Guidance was therefore sought from Smith (2011) regarding appropriate presentation of participant quotes, as dictated by the size of the sample. An appropriate level of interpretation is also evident from the 'unpacking' of participants' quotes and development of the conceptual framework. With this in mind, this thesis provides what Smith would classify as '*good*' IPA research (2011).

### 11.0.3 - Transparency and coherence

The third of Yardley's principles (2008) relates to the transparency and clarity of the research process. This has been achieved throughout this study and documented within this thesis. Firstly, the two narrative literature reviews presented in Chapters 2 and 3 were systematically conducted; explicit detail has been provided at the beginning of each chapter regarding the review process. Secondly, the way in which participants were recruited using a plethora of recruitment strategies, has also been comprehensively documented within the methods chapter (Chapter 5). Also provided within this chapter is extensive detail regarding the data analysis process, including rigour being enhanced through sections of data being 'independently audited' by my supervisory team (Smith, Flowers and Larkin, 2009). As suggested by the COREQ, detail was also provided in this chapter regarding the use of qualitative data analysis software, how data were coded and, crucially, how themes were developed (Tong, Sainsbury and Craig, 2007). Findings were then synthesised into a coherent narrative within each of the findings chapters to elucidate the key findings. Rigour was further upheld within these chapters by inclusion of line references to the raw transcript data, and use of pseudonyms as participant identifiers (Tong, Sainsbury and Craig, 2007). It is argued that such comprehensive documentation of how the study was conducted, within this thesis, promotes a high level of reliability allowing potential replication of the study.

Developing a coherent argument has been evidenced within the discussion chapter with themes from the three findings chapters being logically synthesised to generate overall study conclusions (Smith, Flowers and Larkin,

2009). This has partly been achieved through the development of the conceptual framework which provides applicability of findings in relation to existing theoretical and empirical knowledge (Yardley, 2008). It is therefore clear that the focal topic of this study and thesis, is the use of digital legacies with people affected by MND.

#### 11.0.4 - Impact and importance

The final principle of assessment for good quality qualitative research is whether it is *'interesting, important or useful'* (Smith, Flowers and Larkin, 2009, p.183). Clearly the interest and acceptance of digital legacies within the context of MND in support of this study provides some justification for interest in the research. A number of charities and organisations from all across the world assisted in advertising information about the study to support participant recruitment. Furthermore, being invited to present and disseminate information about the study to a number of academic and 'lay' audiences, evidences a clear interest in the research topic. It is apparent that a growing number of people are beginning to recognise the importance and value of digital legacies within MND populations. Since raising awareness of this study, the MND Association for England, Wales and Northern Ireland has begun including information about creating a digital legacy on its website, thus indicating its perceived value within the field of MND (MND Association, 2017c).

Additional impact has been noted from the perspective of healthcare professionals, specialists and experts. Following interviews with these participants, and presenting the study during a number of MND specialist interest groups, staff working with people and families affected by MND are now building the concept of digital legacies into their practice. Some of the MND nurses who participated in the study, now discuss the possibility of creating a digital legacy during initial consultations after plwMND have been diagnosed. Similarly, hospice staff and child bereavement specialists have arranged digital legacy training sessions following their participation in the study to provide optimal support to their patients and clients. This suggests that there is scope for the findings from this study to be transferred to alternative, non-MND populations (e.g. Huntington's, cancer, dementia).

### **11.1 - Summary of strengths and limitations**

The first section of this chapter has highlighted the various strengths and limitations of the study based upon Yardley's assessment of qualitative research (2008), the assessment of IPA research (Smith, 2011), and the COREQ (Tait, Sainsbury and Craig, 2007). These acknowledged strengths and limitations will form the basis for recommendations regarding future policy, practice and research, which will be delineated in the following section of this chapter.



## 11.2 - Recommendations for future policy, practice and research

The following section will provide a number of suggested recommendations for future policy, practice and research, based upon findings from this study. It should be noted that this is not an exhaustive set of recommendations. Instead, I provide suggestions arising from some of the main findings that have been generated from the study.

### 11.2.1 - Recommendations for policy

As suggested by the NICE guidance for assessment and management of MND, it is recommended that plwMND are provided with appropriate psychological and social care support (NICE, 2016a). As stipulated in Figure 18 below, the current guidance delineates a number of topics which should be discussed by multidisciplinary teams with plwMND.

*Figure 18- Motor neurone disease: assessment and management  
(NICE, 2016a)*

#### **1.6 Psychological and social care support**

- 1.6.1 During multidisciplinary team assessments and other appointments, discuss the psychological and emotional impact of MND with the person and ask whether they have any psychological or support care needs. Topics to discuss may include the following:
- Their understanding of MND and how it affects daily living.
  - Accepting and coping with the diagnosis and prognosis, including concerns and fears about dying.
  - Their ability to continue with current work and usual activities.
  - Adjusting to changes in their life and their perception of self.
  - Changes in relationships, familial roles and family dynamics.
  - Sexuality and intimacy.
  - Concerns about their family members and/or carers.
  - Decision-making. [new 2016]

It is clear that these recommended topics are important to be discussed with plwMND. However, currently, there are no suggestions regarding potential ways in which multidisciplinary teams may help plwMND to resolve these concerns. Based upon findings from this study, it is argued that creating a digital legacy may be one way to attend to a number of these discussion topics. For example, creating a digital legacy provided a way for participants living with the disease to ruminate on their illness, thus contributing to '*accepting and coping with the diagnosis*' (bullet point two). Furthermore, recording the digital legacy provided a way for participants in the study to attend to concerns regarding children and young people in their family (bullet point 7).

In light of this, one recommendation from the study is to provide actionable 'solutions' to the already published discussion topics for plwMND. Such an idea has begun to be implemented by the MND Association for England, Wales and Northern Ireland. For example, documentation for plwMND regarding 'planning ahead', now includes information about recording a digital legacy (MND Association 2017c). This would allow members of a multidisciplinary team to initiate discussion with plwMND through referring to a published set of solutions, alongside these existing discussion topics.

An additional recommendation relates to the existing policy regarding the provision of information and support to plwMND at the point of diagnosis (NICE, 2016b). This states that plwMND are given information about their diagnosis by a consultant neurologist who possesses an expertise of the

disease. It is therefore recommended that these specialists are aware of activities, such as creating a digital legacy, which can be conveyed to plwMND during these early consultations. This would allow specialists to '*plant the seed*' within plwMND (Grace, palliative care therapist, page 220). Moreover, this may offer a small element of optimism regarding a proactive response to receiving the terminal diagnosis. One way in which this could be actioned is through disseminating written information to staff working with plwMND about the concept of digital legacies. This could adopt the form of a written document that is given to healthcare professionals who currently work within MND care and research centres. Alternatively, this information could be incorporated into one of the annual MND Association care coordinator meetings. This would provide an opportunity for attendees to discuss digital legacies, and also prompt information to later be cascaded to other healthcare professionals who are not in attendance.

#### 11.2.2 - Recommendations for practice

A clear recommendation for practice is to increase the general knowledge of healthcare and other professionals who work with plwMND regarding the option of creating a digital legacy. As described throughout this thesis, the concept of digital legacies within palliative care, is still somewhat in its infancy. Consequently, many healthcare professionals working within this context, are unaware of what a digital legacy is, and, how plwMND may create one. It is therefore clear that increasing this knowledge across the workforce would be

advantageous, with one potential solution being the creation of a digital legacy specific e-learning course. Developing this further, it is also recommended that healthcare professionals become aware that creating a digital legacy must coincide with the 'windows of opportunity' that have been identified from this study. This would reduce the possibility of plwMND *'miss[ing] the boat'*, and their opportunity to create a digital legacy (Rose, Chapter 8, page 225).

One way in which this could be actioned is through healthcare professionals informing plwMND about creating a digital legacy during early consultations. Discussing the idea during the early stages of the disease trajectory would promote optimal use of each 'window of opportunity'. Therefore, including some discussion within advance care planning (ACP) conversations would be advisable. ACP conversations will often include exploration of the plwMND's concerns, values and goals for the remainder of their life (The National Council for Palliative Care, 2008). As such, suggesting the idea of creating a digital legacy may not only attend to these ACP concerns, but may also stimulate additional conversation between the plwMND and healthcare professional.

Based upon findings from the study, it is also clear that both creating and using a digital legacy, can be emotionally evocative. Therefore, an additional recommendation for practice is that plwMND, and bereaved young people, are provided with accessible emotional support, in the event it is required. This may be provided by existing members of the multidisciplinary team for plwMND, or child bereavement specialists for the young people.

### 11.3.3 - Recommendations for future research

Whilst a number of important findings have been generated from the study, it is clear that future research would be beneficial. Notably, the findings from the study suggest there to be an optimal window of opportunity to create the digital legacy. However, it remains unclear when this window might be within a plwMND's disease trajectory. Further research would be valuable to ascertain precisely when this might be in order to provide optimal support for future plwMND who wish to create a digital legacy.

Similarly, there seems to also be an optimal window for bereaved young people to access and use a digital legacy. However, findings from this study did not elucidate potential benefits for bereaved young people in having access to a digital legacy immediately after the death of a plwMND. It would therefore be useful for future research to adopt a longitudinal approach to investigate the experiences and use of digital legacy by bereaved young people during key points throughout their grief journey. This would also allow investigation of the young person's potentially changing relationship with the digital legacy throughout their grief journey. Whilst recruitment of participants was challenging for the existing study, it is anticipated that future research with this population will become gradually easier due to the rise in affordable/accessible technologies in which digital legacies can be created.

It would also be useful for future research to investigate the use of a digital legacy within structured talking therapies for bereaved young people. It was suggested that temporarily blocking certain aspects of the digital legacy in

accordance with the young person's sense preferences might be useful. While this concept would be useful for child bereavement practitioners to consider before use of a digital legacy in therapeutic contexts, further research is undoubtedly required.

The findings from the study also outlined a discrepancy between the content recorded within the digital legacy by plwMND, and what was desired by bereaved young people. It would be advantageous for future research to ascertain what bereaved young people wished to be included within the plwMND's digital legacy. This information could then be collated and used to provide guidance for plwMND to refer to before they begin to record their digital legacy. In turn, this may reduce a sense of plwMND feeling overwhelmed during the recording process, something which has been identified within this study.

Finally, 'The Model of Reciprocal Bonds Formation' and coining of the term 'autobiographical chapter', are important findings generated from this study. The model offers a theoretical underpinning to guide the creation of a legacy by people approaching death which can be given to their bereaved family members in the future. Whilst it can be suggested from this study that creating an autobiographical chapter is beneficial for plwMND, future research is recommended in order to investigate the transferability of the concept to people with alternative terminal illnesses. Due to the versatility of the model, it is anticipated that any differences between illnesses would be notable within the challenges of creating the autobiographical chapter (digital legacy). For

example, a patient who has been diagnosed with terminal cancer, will be confronted with alternative windows of opportunity to a plwMND. Future research would be beneficial to highlight the different types of challenges people face when creating their autobiographical chapter/digital legacy, as shaped by the type of terminal illness.

### **11.3 - Final word**

Whilst creating, or using, a digital legacy by people affected by MND generates a number of challenges and barriers, it also provides a plethora of benefits. Creating a digital legacy provides a way for plwMND to capture their identity and biography which enables a continuation of existence after their death, albeit in a digital form. Similarly, bereaved young people gain a sense of comfort from using a digital legacy and being able to see, hear and learn about the plwMND who has died. It is argued that this provides the young person with an additional means of support throughout their bereavement.

To date, this is the first study to investigate the use of digital legacies with people affected by MND. It is anticipated that this will be a growing area of research interest within the coming years due to the sharp increase in accessibility and affordability of digital technologies. The hope of this study is that it provides preliminary evidence that creating a digital legacy alleviates an element of existential concern for plwMND, and additionally, provides a method of support for young people bereaved by the disease.

***Recording the digital 'you', can provide comfort to the future 'me'.***

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## **Appendices**

*Appendix 1- Summary review table (literature review one: legacy interventions)*

Glossary of Quantitative Tools	
Abbreviation	Full name
BGEIQ	The Brief Measure of Generativity and Ego-Integrity
BMMRS	Brief Multidimensional Measure of Religion and Spirituality
CES-D	Center for Epidemiological Studies- Depression
CSS-R	Caregiver Stressors Scale- Revised
DDRS	Desire of Death Rating Scale
DTPFQ	Dignity Therapy Patient Feedback Questionnaire
ESAS	Edmonton Symptom Assessment Scale
FACIT-Sp	Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Scale
FACT-G	Functional Assessment of Cancer Therapy- General
GDI	Good Death Inventory
GDS	Geriatric Depression Scale
HADS	Hospital Anxiety and Depression Scale
HHI	Herth Hope Index
PDI	Patient Dignity Inventory
QoLS	Quality of Life Scale
SELT-M	Skalen zur Erfassung von Lebens qualitat bei Tumorkranken- Modified
SISC	Structured Interview for Symptoms and Concerns

Life Review 1/2				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings <i>(indicator of quality from the JBI tool appropriate for the study type)</i>
Ando, M., Morita, T., Ahn, S., Marquez-Wong, F. and Ide, S., 2008	Japan Korea USA	n=20 (cancer)	<i>Quantitative</i> >FACIT-sp >HADS	>Cultural differences regarding primary concerns of people approaching EoL (10/10)
Ando, M., Morita, T., Akechi, T. and Okamoto, T., 2010	Japan	n=68 (cancer)	<i>Quantitative</i> >FACIT-sp >HADS >GDI	>Short-Term Life Review was effective in improving spiritual wellbeing and alleviating psychosocial distress (6/9)
Ando, M., Morita, T., Akechi, T. and Takashi, K., 2012	Japan	n=34 (cancer)	<i>Qualitative</i> >Life review narratives analysed	>Important factors were recognised as; human relationships, raising children, educational achievements, and concerns about children's future (6/10)
Ando, M., Morita, T., Okamoto, T. and Ninosaka, Y., 2008	Japan	n=30 (cancer)	<i>Quantitative</i> >FACIT-Sp >HADS	>Short-Term Life Review feasible with terminally ill cancer patients and effective in improving spiritual and psychosocial well-being (8/9)
Ando, M., Tsuda, A. and Morita, T., 2007	Japan	n=12 (cancer)	<i>Quantitative</i> >SELT-M	>QoL and spirituality scores increased after life review intervention (6/9)
Chen, Y., Xiao, H., Yang, Y. and Lan, X., 2016	(China)	11 articles	Systematic review >MEDLINE, Cochrane, EMBASE, CINAHL, PsycINFO, CNKI	>Life review can decrease depressive symptoms, improve QoL and enhance self-esteem for patients with a terminal illness (11/11)

Life Review cont. 2/2				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Haber, D., 2006	(USA)	140 articles	<i>Selective literature review</i> >MEDLINE, CINAHL, PsycINFO	> Structured around one or more life themes (family, childhood, work etc). Likely to be evaluation memories and how they contribute to the person's meaning of life (7/11)
Keall, R., Clayton, J. and Butow, P., 2015	(Australia)	14 articles	<i>Systematic review</i> >PubMed, MEDLINE, Web of Science, CINAHL, Scopus, PsycINFO	>Interventions could be conducted days to months before patient death, within one to eight sessions, each lasting 15-160 minutes >Life review addressed existential and spiritual concerns for patients (11/11)
Kwan, C., Ng, M. and Chan, C., 2017	(China)	7 articles	<i>Integrative review</i> >MEDLINE, PubMed, CINAHL, PsycINFO	>Shorter time frame of life review intervention required for patients with rapidly progressing illnesses (9/11)
Wang, C., Chow, A. and Chan, C., 2017.	(Hong Kong)	7 articles	<i>Systematic review &amp; meta-analysis</i> >CINAHL, Cochrane, PsychINFO, PubMed, Web of Science	>No significant long term effects of life review on patient spiritual wellbeing, or, psychological distress >Significant findings identified for life review to enhance meaning of life (10/11)

Dignity Therapy 1/4				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Aoun, S., Chochinov, H. and Krisjanson, 2014.	Australia	n=27 (plwMND)	Quantitative >PDI >ALSAQ-5 >FACIT-sp12 >Herth Hope Index	>no changes in hope, dignity, spirituality at the group level, post intervention >time/training/costs suggests impractical for smaller organisations to implement DT with plwMND >DT to be carried out early on in the disease trajectory (10/11)
Bentley, B., O'Connor, M., Kane, R. and Breen, L., 2014	Australia	n=29 (plwMND)	Quantitative >HHI >PDI >FACIT-sp-12 >ALSAQ-5 >ALSFRS	>Feasible and acceptable for plwMND. Issues with therapist time and communication difficulties (6/8)
Bentley, B., O'Connor, M., Shaw, J. and Breen, L., 2017	(Australia)	39 articles	Systematic review >PubMed, CINAHL, PsycINFO, Scopus	>DT a costly and time rich intervention >only one study found DT to reduce distress (9/11)
Bernat, J., Helft, P., Wilhelm, L., Hook, N., Brown, L., Althouse, S. and Johns, S., 2015	USA	n=58 (cancer)	Quantitative >FACIT-sp >PDI >Developed a satisfaction scale	>Online portal was a feasible/acceptable method of abbreviated DT >time/costs were limited due to minimal transcription (8/10)

Dignity Therapy cont. 2/4				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Chochinov, H., Hack, T., Hassard, T., Kristjanson, L., McClement, S. and Harlos, M., 2005	Australia Canada	n=100 (mainly cancer)	Quantitative >ESAS >QoLS	>DT reduced suffering and distress for patients approaching EoL >Patients found life more meaningful, and increased sense of purpose following DT (8/10)
Chochinov, H., Kristjanson, L., Breitbart, W., McClement, S., Hack, T., Hassard, T. and Harlos, M., 2011	Australia Canada USA	n=441 (mainly cancer)	Quantitative >FACIT-sp >PDI >HADS >QoLS >modified ESAS >DTPFQ	>DT improved; EoL experience, sense of dignity, QoL, sense of appreciation and helpfulness to family (11/13)
Donato, S., Matuoka, J., Yamashita, C. and Salvetti, M., 2016.	(Brazil)	11 articles	Systematic review >PubMed, Cochrane, Scopus, CINAHL, Web of Science, Lilacs	>DT increased sense of dignity, will to live, and sense of purpose >increased acceptance of death and discussion around EoL goals (10/11)
Hall, S., Goddard, C., Opio, D., Speck, P. and Higginson, I. 2011	UK	n=60 (cancer)	Quantitative >PDI >HHI >GDS	>DT did not reduce distress, but enhanced EoL experience >Therapist feasibility- time consuming (11/13)

### Dignity Therapy *cont.* 3/4

<b>Authors</b>	<b>Country</b>	<b>Sample (terminal illness)</b>	<b>Methodology/ data collection</b>	<b>Key findings</b> <i>(indicator of quality from the JBI tool appropriate for the study type)</i>
Hall, S., Goddard, C., Speck, P. and Higginson, I., 2012	UK	n=60 (unspecified)	<i>Qualitative</i> >Semi-structured interviews	>DT made participants feel 'useful' and 'important' >Reminded families of positive aspects of patient's life (9/10)
Houmann, L., Chochinov, H., Kristjanson, L., Petersen, M. and Groenvold, M. 2014	Denmark	n=80 (cancer)	<i>Quantitative</i> >PDI >HADS >SISC >DTPFQ	>DT heightened sense of purpose >DT had made life more meaningful and lessened suffering (8/10)
Juliao, M., Barbosa, A., Oliveira, F., Nunes, B. and Vaz Carneiro, A., 2013	Portugal	n=60 (unspecified)	<i>Quantitative</i> >HADS	>Beneficial effect on depression and anxiety symptoms (11/13)
Juliao, M., Oliveira, F., Nunes, B., Carneiro, A. and Barbosa, A., 2014	Portugal	n=80 (mainly cancer)	<i>Quantitative</i> >HADS	>Beneficial effect on depression and anxiety symptoms for patients approaching EoL (13/13)
Juliao, M., Oliveria, F., Nunes, B., Carneiro, A. and Barbosa, A., 2017	Portugal	n=80 (mainly cancer)	<i>Quantitative</i> >DDRS >PDI	>Beneficial effect on psychological distress for patients approaching EoL (11/13)
Li, H., Richardson, A., Speck, P. and Armes, J., 2014	Taiwan	n=19 (9: cancer) (10: HCP's)	<i>Qualitative</i> >In-depth interviews	>Cultural differences regarding DT and concerns for patients (8/10)



Dignity Therapy cont. 4/4				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings <i>(indicator of quality from the JBI tool appropriate for the study type)</i>
Martinez, M., Arantzamendi, M., Belar, A., Carrasco, J., Carvajal, A., Rullan, M. and Centeno, C., 2017	(Spain)	28 articles	Systematic review >PubMed, CINAHL, Cochrane, PsycINFO	>DT is beneficial in reducing symptoms of distress, anxiety and depression >Improve EoL experience (11/11)
Montross, L., Winters, K. and Irwin, S., 2011	USA	n=27 (mainly cancer)	Qualitative >Analysis of legacy transcripts	>Common themes discussed in legacy- autobiographical information, love, hobbies, career, children (8/10)
Sposato, L., 2016	(USA)	10 articles	Systematic review >CINAHL, Ovid, PubMed	>DT as a holistic intervention to decrease anxiety, depression and suffering for EoL patients (8/11)
Tait, G., Schryer, C., Mcdougall, A. and Lingard, L., 2011	Canada	n=12 (unspecified)	Qualitative >Semi-structured interviews	>Patients reflected upon life before illness, transition from healthy to ill, and, messages for loved ones (7/11)
Vukasnovic, D., Green, H., Dyck, M. and Morrissey, S., 2016	Australia	n=70 (cancer)	Quantitative >PDI >BGEIQ >FACT-G	>Positive effect on sense of generativity, meaning and acceptance near EoL (13/13)

### Alternative Interventions 1/2

<b>Authors</b>	<b>Country</b>	<b>Sample (terminal illness)</b>	<b>Methodology/ data collection</b>	<b>Key findings</b> <i>(indicator of quality from the JBI tool appropriate for the study type)</i>
Allen, R., 2009	USA	n=34 (17: patients) (17: family carers)	<i>Qualitative</i> >Reflection on three cases (patient/carer dyad)	>Promoting family communication and increased positive emotional experiences for both patient and carer (7/10)
Allen, R., Hilgeman, M., Ege, M., Shuster, J. and Burgio, L., 2008	USA	n= 62 (31: patients) (31: family carers)	<i>Quantitative</i> >ESAS >BMMRS >CES-D >CSS-R	>Creating a legacy improved family communication, increased patient spiritual meaning and reduced caregiver stress (7/9)
Cadrin, M., 2006	Canada	n= 3 (one plwMND)	<i>Qualitative</i> >Reflection on three cases	>Music can stimulate the expression of memories, emotions and feelings during the creation of a legacy (5/8)
Keim-Malpass, J., Adelstein, K. and Kavalieratos, D., 2015	USA	n=5 (cancer)	<i>Qualitative</i> >Analysis of online blogs	>Blogs provided a space to create an online legacy and process grief (8/10)
Kogan, A., Kobashigawa, W., Taguchi, J. and Carter, K., 2017.	USA	n=51 (unspecified)	<i>Quantitative/qualitative</i> >Evaluation survey	>Video autobiography is a feasible approach to reminiscence and positively experienced by patients (7/8)
RecordMeNow, 2017	Canada	n=100 (unspecified)	<i>Qualitative</i> >Semi-structured interviews	>Creating a video legacy is well accepted and appreciated by bereaved children (4/6)

Alternative Interventions <i>cont. 2/2</i>				
Authors	Country	Sample (terminal illness)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Redhouse, R., 2014	UK	n=1 (cancer)	Qualitative >Case study	>Drama therapy used as an effective way to assist with the creation of a life story (5/8)
Sato, Y., 2011	USA	n=1 (cancer)	Qualitative >Case study	>Music helped to lift patient mood of and stimulated the expression of feelings, emotions and memories (6/6)

Appendix 2- Summary review table (literature review two: continuing bonds)

Continuing bonds for bereaved young people 1/4				
Authors	Country	Sample (age range in years)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Biank, N. and Werner-Lin, A., 2011	USA	n=1 (4-14)	Qualitative >Case study	>Young people reinterpret the deceased's life and personality as they grow up and gain develop cognitive and emotional skills. (8/8)
Brewer, J., and Sparkes, A., 2011	UK	n=13 (9-25)	Qualitative >Semi-structured interviews	>Young people use many senses to 'bridge' a connection with the deceased and continue bonds (9/10)
Christ, G., Siegel, K. and Christ, A., 2002	(USA)	(unspecified)	Literature review >(unspecified)	>Bereaved young people engaged in a process of 'reconstitution' by developing a new relationship with the deceased (4/6)
DeVries, B. and Rutherford, J., 2004	USA	n=244 online memorials	Qualitative >Analysis of online posts	>Majority of posts were written as letters to the deceased by bereaved young people (8/8)
Field, N., Gao, B. and Paderna, L., 2005	(USA)	(unspecified)	Literature review >(unspecified)	>Symbolic use of objects to continue bonds with the deceased which are gradually diminishes over time as the connection becomes internalised (4/6)

### Continuing bonds for bereaved young people *cont. 2/4*

Authors	Country	Sample (age range in years)	Methodology/ data collection	Key findings (indicator of quality from the JBI tool appropriate for the study type)
Foster, T., Gilmer, M., Davies, B., Dietrich, M., Barrera, M., Fairclough, D., Vannatta, K. and Gerhardt, C., 2011	USA	n=39 (3-12)	<i>Quantitative/ qualitative</i> >Questionnaire >Semi-structured interview	>Use of purposeful reminders such as photos, toys and scrapbooks, enabled young people to 'go back to the memory' and continue bonds (6/10)
Hansen, D., Sheehan, D., Stephenson, P. and Mayo, M., 2016	USA	n=9 (12-18)	<i>Qualitative</i> >Semi-structured interviews	>Young people continue bonds in three ways; encounters, mementos, inner guide (7/10)
Irwin, D., 2015	USA	n=1270 Facebook posts	<i>Qualitative</i> >Analysis of online posts	>Facebook commonly used to converse with the deceased and describe events that were interpreted as visits from beyond the grave (6/9)
Nickman, S., Silverman, P. and Normand, C., 1998	USA	n=24 (10-12)	<i>Qualitative</i> >Semi-structured interviews	>Connection is maintained through an inner representation which provides a 'bridge' with the deceased (9/10)
Normand, C., Silverman, P. and Nickman, S., 1996	USA	n=24 (10-12)	<i>Qualitative</i> >Semi-structured interviews	>Young people often talked to deceased parents and 'heard' them responding during the earliest stages of loss. Objects and mementos gradually used less over time. (8/10)

### Continuing bonds for bereaved young people *cont. 3/4*

<b>Authors</b>	<b>Country</b>	<b>Sample (age range in years)</b>	<b>Methodology/ data collection</b>	<b>Key findings</b> (indicator of quality from the JBI tool appropriate for the study type)
Packman, W., Horsely, H., Davies, B. and Kramer, R., 2006.	(USA)	(unspecified)	<i>Literature review</i> >(unspecified)	>A careful balance of developing 'healthy bonds' and not becoming preoccupied the death. Continuing bonds through sensing a 'presence' of the deceased (5/6)
Pearce, C., 2008	UK	n=2 (15, 17)	<i>Qualitative</i> >Auto-ethnography	>Memories and identity of deceased mother have been relocated and selected in accordance with mood and situation (8/9)
Pennington, N., 2013	USA	n=43 (18-24)	<i>Qualitative</i> >Semi-structured interviews	>Young people maintained a connection with the deceased through writing on their Facebook profile wall (7/10)
Root, B. and Exline, J., 2014.	(USA)	(unspecified)	<i>Literature review</i> >(unspecified)	>Spontaneous connections from the deceased may be distressing for young people, emphasising a lack of control in when continuing bonds happen (5/6)
Saldinger, A., Cain, A., Porterfield K. and Lohnes, K., 2004	USA	n=58 (6-16)	<i>Quantitative/ qualitative</i> >Questionnaire >Semi-structured interview	>Legacy items created by dying parent (letters, videos) can be revisited by the young person as required and in accordance with developmental capabilities (6/10)
Silverman, P., Baker, J., Cait, C. and Boerner, K., 2002	USA	n=120 (6-17)	<i>Qualitative</i> >Semi-structured interviews	>Bereaved young people at 'high risk' may not always develop positive internal representations of the deceased. A presence of 'negative legacies' (8/10)

**Continuing bonds for bereaved young people cont. 4/4**

<b>Authors</b>	<b>Country</b>	<b>Sample (age range in years)</b>	<b>Methodology/ data collection</b>	<b>Key findings</b> <i>(indicator of quality from the JBI tool appropriate for the study type)</i>
Simpkins, S. and Myers-Coffman, K., 2017	USA	n=3 (19-38)	<i>Qualitative</i> >Semi-structured interviews	>Memories of the deceased were often evoked through stimulation of senses, mainly smells and through sound of certain songs (8/10)
Sirrine, E., Salloum, A., and Boothroyd, R., 2017.	USA	n=50 (11-17)	<i>Quantitative</i> >Two-track bereavement questionnaire (TTBQ) >Spiritual Well Being Scale (SWBS)	>Bereaved young people with increased symptomatology and immediate relationship with the deceased were more likely to maintain a continued bond with deceased (7/9)
Wood, L., Byram, V., Gosling, S. and Stokes, J., 2012	UK	n=10 (8-15)	<i>Qualitative</i> >Semi-structured interviews	>Use of mementos, photographs, memory boxes provide bereaved young people with a sense of control regarding where and when to evoke memories (9/10)

## Appendix 3- FREC approval letter

Edge Hill  
University

Oliver Clabburn

28<sup>th</sup> July 2015

Dear Oliver,

Thank you for submitting your revised ethics application 'Investigating the views and experiences of using a digital legacy with people affected by Motor Neurone Disease (MND)' (Project Ref: FOHS114) to the Faculty of Health & Social Care Research Ethics Committee.

I have pleasure in informing you that your re-submission has been reviewed by two ~~reviewers~~ and myself, and recommended that your study is granted Faculty of Health & Social Care research ethics approval, subject to the following conditions:

1. Ethical approval covers only the original study for which it is sought. If the study is extended, changed, and / or further use of samples or data is needed the Committee Administrator, Daniel Brown, must be contacted for advice as to whether additional ethical approval is required.
2. If the project requires NHS Permissions and/or NHS ethical approval, please forward evidence of the approval(s) to Daniel Brown ([browdan@edgehill.ac.uk](mailto:browdan@edgehill.ac.uk)) before commencing the study

The Principal Investigator is responsible for ensuring that all data are stored and ultimately disposed of securely in accordance with the Data Protection Act (1998) and as detailed within the approved proposal.

The study documentation that has been reviewed and approved is detailed below:

FREC Proposal	Version 2, 25/06/15
Phase 1, Consent Form	Version 2, 25/06/15
Phase 1, Interview Topic Guide	Version 2, 25/06/15
Phase 1, Invitation Letter	Version 1, 27/05/15
Phase 1, Participant Information Sheet	Version 2, 25/06/15
Phase 2, Assent Form for Participants under 16yrs	Version 2, 25/06/15
Phase 2, Interview Topic Guide	Version 1, 27/05/15
Phase 2, Invitation Letter	Version 2, 25/06/15
Phase 2, Parent Consent Form for Participants Under 16yrs	Version 2, 25/06/15
Phase 2, Parent Information Sheet	Version 2, 25/06/15
Phase 2, Participant Consent Form Over 16yrs	Version 2, 25/06/15
Phase 2, Participant Information Sheet (11-15yrs)	Version 2, 25/06/15
Phase 2, Participant Information Sheet (16-24yrs)	Version 2, 25/06/15
Phase 2 & 3, Support Services Sheet	Version 1, 27/05/15

Phase 3, Assent Form for Participants under 16yrs	Version 2, 25/06/15
Phase 3, Consent Form for Participants over 16yrs	Version 2, 25/06/15
Phase 3, Interview Topic Guide	Version 1, 27/05/15
Phase 3, Invitation Letter	Version 2, 25/06/15
Phase 3, Parent Information Sheet	Version 2, 25/06/15
Phase 3, Parental Consent Form for Participants under 16yrs	Version 2, 25/06/15
Phase 3, Participant Information Sheet (11-15yrs)	Version 2, 25/06/15
Phase 3, Participant Information Sheet (16-24yrs)	Version 2, 25/06/15

Yours sincerely



Dr Lucy Bray

Acting Chair of Faculty of Health & Social Care Research Ethics Committee  
Edge Hill University  
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## Appendix 4- HRA approval letter



Mr Oliver Clabbum  
PhD Student  
Edge Hill University  
Faculty of Health and Social Care  
Edge Hill University  
Ormskirk  
L394QP

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

17 May 2018

Dear Mr Clabbum

### Letter of HRA Approval

Study title:	Investigating the use of digital legacies with people affected by Motor Neurone Disease.
IRAS project ID:	197318
Protocol number:	n/a
REC reference:	16/NW/0282
Sponsor	Edge Hill University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

#### Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.


Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. Please read **Appendix B** carefully, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

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## Appendix 5- Example of a participant information sheet (plwMND)



Edge Hill University

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**Participant Information Sheet**

**Phase 1: Investigating the experiences of people living with Motor Neurone Disease (MND) creating a digital legacy.**

Research Team: Oily Clabburn, Prof. Mary O'Brien, Prof. Barbara Jack and Dr. Kate Knighting  
Email: clabburo@edgehill.ac.uk

**Introduction**

Thank you for taking the time to read this Information sheet which has been given to you as you have indicated that you are interested to find out a little more about the study. The project is being carried out by Oily with the support of his supervisory team. Oily has a specific research interest in children and young people who care for a family member with MND after experiencing it himself. The research is being supervised by Mary, Barbara and Kate who together have extensive research experience in the field of MND, palliative care and family carers.

You are being invited to take part in an interview to explore your experiences of creating a digital legacy for a child or young person in your family. Before you make your decision, it is important that you are aware of the purpose behind the research and how it will be carried out. Please take your time to read the information and discuss the project with others if you wish. If you have any additional questions or require further information, please do not hesitate to contact Oily or another member of the research team.

**What is a digital legacy?**

A 'digital legacy' is a selection of videos that have been purposefully recorded for a child or young person in your family. A digital legacy is unique to each person with some people recording things like bed-time stories, discussing items in a memory box, or perhaps more structured videos about their life, memories and achievements.

Investigating the use of a digital legacy with people affected by MND  
Phase 1, Participant Information Sheet, Version 5, 22 December 2016

Page 2 of 6

**What is RecordMeNow?**

Whilst some people prefer to record lots of different types of videos, other people may prefer to follow a structured format. There are many digital legacy programmes that allow users to record memories, achievements and messages for loved ones. RecordMeNow is one such programme which is free to download from [www.recordmenow.org](http://www.recordmenow.org) and provides prompting questions allowing users to video record responses specifically for children and young people. The prompting questions are based upon research that was carried out by RecordMeNow with children and young people who had lost either one or both of their parents. The research identified the common questions that the young people wish they knew about their parent such as achievements, memories and family life. RecordMeNow provides these questions as prompts which can be modified, deleted or added to as required. Upon completion, the recorded messages can then be copied onto a DVD or digital source to be given to a child in your family.

**What is the aim of this study?**

The research team aims to explore your experiences of creating a digital legacy whilst living with MND. It will also investigate how you feel that the digital legacy will support the children and young people in your family whilst they care, and additionally when you are no longer here.

**Why have I been invited to take part?**

You have been invited to take part in the study as you have indicated that you are English speaking, have been diagnosed with MND, and have created or are interested in creating a digital legacy for a child or young person in your family. This phase of research will investigate your experiences of creating a digital legacy in addition to gaining your views on its usage by young people who currently provide care or will be bereaved in the future.

**Do I have to take part?**

No, it is up to you to decide whether you would like to take part. If you do wish to participate, you have the right to withdraw from the study at any time without having to give a reason. If you decide that you would like to withdraw at a later date, any information that you have provided will not be included in the study if you do not wish it to be.

Investigating the use of a digital legacy with people affected by MND  
Phase 1, Participant Information Sheet, Version 5, 22 December 2016

#### Can I use RecordMeNow without taking part in the study?

Yes, the study and the research team are completely independent from RecordMeNow and do not represent the app in anyway. It is free to download directly from [www.recordmenow.org](http://www.recordmenow.org), or the Apple App store. RecordMeNow is not specifically for people who have been diagnosed with MND and is intended for anyone to use who wishes to leave a digital legacy for young people in their family. With this in mind, any reference to RecordMeNow in this study is to signpost people to one of many resources available online to help create a digital legacy.

#### Can I still take part if I have not used RecordMeNow to create my digital legacy?

Yes, we are interested in hearing about all different types of video-legacy that have been specifically recorded for a child or young person in your family. RecordMeNow is just one of many different ways to create a digital legacy.

#### What will happen if I agree to take part?

If you would like to take part in the study, please contact Oily (contact details are at the bottom of this form) who will answer any questions about the research. We will then arrange a convenient time and place to meet. Before the interview, Oily will ask you to sign a consent form to confirm your participation. If you agree, the interview will be audio-recorded in order for it to be transcribed later. The interview will then start with you providing verbal consent of your participation before you and Oily begin to discuss your experiences of creating a digital legacy. Overall, the interview is anticipated to take approximately 30 minutes although it may continue longer if the conversation is flowing meaning the interview will be informal.

If you would like to be interviewed at home, Oily will come to your home. If you would prefer to be interviewed outside of your home, then a suitable location will be agreed. If there are geographical limitations, or if preferred, a Skype interview can be arranged. Your participation and time is greatly appreciated so if at any point during the interview you would like a break, please let Oily know. If talking is problematic and typing is preferred, then email or written communication can also be arranged in which the same information will be gathered in written form. You should also decide whether you would prefer to speak to Oily alone, or with the presence of another adult who is not the young person that your digital legacy has been created for.

#### What are the possible disadvantages and risk in taking part?

A possible risk is that reflecting upon memories, terminal illness and death can often be upsetting. If this happens, Oily will pause the interview, move onto another question, end the interview or reschedule it for another day. If at any point throughout the interview you wish to stop, have a break, or ask another adult to join you, please let Oily know. At the bottom of this information sheet are also details for MND Connect who may also provide support, advice and guidance if required.

#### What are the possible benefits?

The experiences you share of creating a digital legacy could help other people who also have MND, whilst also creating a future resource for their children. The findings from this research will help inform people with MND who are considering making a digital legacy for a child in their family.

#### Will my taking part be kept confidential?

Yes. Any information about you and/or your family will have names changed and addresses removed. The only people that will know what is said will be the research team. All electronic data and audio recordings will be stored on a password protected server at the University and then destroyed once the research is completed. Any written information including your personal details will be kept strictly confidential to the research team and locked away in a secure location for a period of 10 years until being destroyed securely. Only if the research team uncover information that suggests that you or others are at risk of coming to any harm, will this confidentiality be broken. The procedures for handling, processing, storing and destroying both paper and electronic data from the study are compliant with the Data Protection Act 1998.

#### What are you going to do with the results of the study?

The results of this study will be written up as part of Oily's PhD thesis. The study will also be published in academic journals and presented at conferences. Summaries will be prepared for dissemination to interested organisations, and, upon request, to the families who take part in the study. You, nor your family will be identifiable in any publication, even if we use your words.

**What if I would like help with my digital legacy?**

If you have decided that you would like to create a digital legacy but feel like you would benefit from some guidance, please let Oily know. We could arrange some time prior to the interview where advice and guidance is provided to help record your videos. If you do receive help with your digital legacy but after feel unable to participate in an interview, please let Oily know. Your participation in the study is voluntary and you are free to withdraw at any point. Alternatively, the interview could be rescheduled for a more appropriate time or day.

**Who is funding the research?**

The research is funded by Edge Hill University as part of a PhD programme of study.

**Who has reviewed the study?**

This study has been reviewed by the by the Faculty of Health and Social Care Research Ethics Committee, Edge Hill University.

**Contact Details**

If you would like to ask any other questions regarding the research, what is expected from you, or you would like to take part in the study please phone Oily on (+44) 01695 654316, email him at [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk) or message through [www.facebook.com/mndlegacy](https://www.facebook.com/mndlegacy)

Alternatively, if you would like to speak to a different member of the research team, you can contact Prof Mary O'Brien on (+44) 01695 650918 or email her at [Obrienm@edgehill.ac.uk](mailto:Obrienm@edgehill.ac.uk)

**What if there is a problem?**

If you are unhappy with the research in any way, please let Oily know in order to try and put things right. If you would prefer to talk to someone else outside of the research team, you can contact Dr Lucy Bray who is a researcher at Edge Hill University on (+44) 01695 657231 or email [brayl@edgehill.ac.uk](mailto:brayl@edgehill.ac.uk)

Any concerns you may have regarding RecordMeNow can be sent directly to [director@RecordMeNow.org](mailto:director@RecordMeNow.org)

Thank you for taking the time to read this information.  
Please keep this information sheet.

**Additional Support****MND Connect**

MND Connect is a free service that offers advice, practical guidance and emotional support. The friendly team can also help direct you towards other services and agencies where needed.

You can call them on (+44) 0808 802 6262 and are open Monday to Friday 9.00am - 5.00pm and 7.00pm -10.30pm, or you can email them anytime [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)

## Appendix 6- Participant information for 11-15 year olds

Page 1 of 3



### Edge Hill University

**Participant Information Sheet (for 11-15 year olds)**

Phase 3: Investigating the views and experiences of bereaved young people using a digital legacy created by a family member who had Motor Neurone Disease (MND).

Research Team: Olly Claiburn, Mary O'Brien, Barbara Jack and Kate Knighting  
Email: clabburo@edgphill.ac.uk

You are being asked if you would like to take part in a study. Before you decide, you need to know why we are doing this study and what will happen. This sheet will tell you all about it.

What is the aim of this study?

The researchers want to find out what young people think about watching and using the digital legacy that has been created using RecordMeNow. This is the computer program that was used to record the video messages made by the person in your family who had MND.

Who is doing the study?

The research is being carried out by Olly who is studying at Edge Hill University and has also lost somebody who had motor neurone disease. Olly is being helped by Mary, Barbara and Kate who are also interested in supporting people who have MND and those that care for them.

Why have I been asked to take part?

You have been asked to take part in the study as somebody in your family had motor neurone disease and recorded video messages using RecordMeNow. Olly would like to ask you about your views and experiences of losing a family member to MND and watching video-messages that have been recorded.

Who else is being spoken to?

Olly will be talking to between 5 and 10 other young people about their experiences of using a RecordMeNow digital legacy after a family member has died from MND.

Investigating the use of a digital legacy with people affected by MND  
Phase 3, Participant Information Sheet (11-15yrs), Version 2, 25 June 2015

What is a 'digital legacy'?

A digital legacy is the DVD of video messages that was made by a person in your family who had MND.



Page 2 of 3

What will happen to me if I say 'yes, I want to take part'?

If you decide to take part, we will arrange a time for Olly to come and talk to you about your experiences. Alternatively we could arrange a Skype interview but it is completely up to you and how you would feel most comfortable and prefer to talk. It is also your decision if you would like to talk to Olly alone, or if you would like a known adult to sit with you. The conversation will be audio-recorded so Olly can remember the important things that you tell him.

Do I have to take part?

No! It is up to you to decide whether or not to take part, no-one will mind if you would rather not take part. If you do take part you can change your mind at any time, without telling anyone why, no-one will mind.

Will anyone else know I'm doing this?

Your parent/guardian will know that you are taking part. Some of the things you say might be used in reports, but no-one will know that it was you that said them. Only the people in the research team will know what you have said, unless you say something which makes us worry about your safety. If this happens, Olly will talk to you about who you might be able to talk to for help, or whether he could talk to someone for you.

What are the good things about taking part?

Your experiences and the information that you share with Olly during the chat could help make things better for other young people who are affected by MND.

Are there any bad things about taking part?

There aren't any bad things about taking part, but sometimes it can be upsetting to talk about somebody who has recently died. If this happens, Olly might move onto a different question or suggest rescheduling the chat for a different day. If at any point you want to have a break, stop taking part in the study, or call for a known adult to sit with you, then please say.



Investigating the use of a digital legacy with people affected by MND  
Phase 3, Participant Information Sheet (11-15yrs), Version 2, 25 June 2015

What will be done with the things I talk about?

Some of the things you tell Olly will be written up in a book he is writing called a thesis. Other things might be used to write articles or make presentations for other people who work with young carers. No-one apart from the research team will know what you have said during the interview because you will be given a pretend name.

Did anyone check the study is OK to do?

Before any study like this can start, it is checked by a group of people from the University. They meet and read everything about the study to make sure that the project is okay to do.

What if I have questions that aren't about the study?

Sometimes when people talk about difficult subjects like motor neurone disease or losing someone who had a disease, they might have some questions but don't know who to ask. Included in this information pack are the details of some free services and ways to contact them.

What if I have some questions about the study?

If you have any questions about the study please talk to your parents/siblings/aunt/uncle/carer or you can phone Olly on (+44) 01695 654316, email him at [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk) or message through [www.facebook.com/mndlegacy](https://www.facebook.com/mndlegacy)



If you would prefer to speak to somebody else in the research team, you can phone Mary (+44) 01695 650918 or email her at [Obrierm@edgehill.ac.uk](mailto:Obrierm@edgehill.ac.uk)

If you have any concerns about the research and do not want to speak to Olly, you can contact Dr Lucy

Bray who is a researcher at Edge Hill University on (+44) 01695 657231 or email [brayl@edgehill.ac.uk](mailto:brayl@edgehill.ac.uk)

If you have any questions or worries about RecordMeNow and do not wish to speak to Olly, you can send them straight to [director@RecordMeNow.org](mailto:director@RecordMeNow.org)



Edge Hill University

### Participant Assent Form (under 16 years old)

Phase 3: Investigating the views and experiences of bereaved young people using a digital legacy created by a family member who had Motor Neurone Disease (MND).

Research Team: Olly Clabburn, Prof. Mary O'Brien, Prof. Barbara Jack and Dr. Kate Knighting

Email: [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk)

Please tick the small box if you agree

1. I have read and understand the Information sheet (Phase 3, Participant Information Sheet (11-15 yrs) Version 2, 25 June 2015) and have been able to ask any questions.	<input type="checkbox"/>
2. I understand that RecordMeNow can be used without having to participate in this study. I also understand that none of the video messages that have been made using RecordMeNow will be accessed and watched by Olly.	<input type="checkbox"/>
3. I understand that I do not have to take part and can stop at any time.	<input type="checkbox"/>
4. I understand that Olly will interview me and I can have a known adult sat with me if I would like.	<input type="checkbox"/>
5. I understand that the interview will be audio-recorded.	<input type="checkbox"/>
6. I am happy for quotes to go into reports or publications and understand that no-one will be able to tell that the quotes were said by me.	<input type="checkbox"/>
7. I am happy for parts of my interview to be used during training by the research team and understand that no-one will be able to tell that it was said by me.	<input type="checkbox"/>
8. I understand that some of the information from this project may have to be looked at by people who supervise Olly and I am happy for them to have access to information collected if necessary.	<input type="checkbox"/>
9. I agree to take part in this project	<input type="checkbox"/>


Name of Participant	Date	Signature
_____	_____	_____
Name of Researcher	Date	Signature
_____	_____	_____

Investigating the use of a digital legacy with people affected by MND

Participant ID Number:

Phase 3, Assent Form for Participants Under 16, Version 2, 25 June 2015

## Appendix 7- Parent/guardian consent sheet for participants under 16 years old


**Edge Hill University**

**Parental Consent Form for Participants Under 16 Years Old**

**Phase 3: Investigating the views and experiences of bereaved young people using a digital legacy created by a family member who had Motor Neurone Disease (MND).**

Research Team: Oily Cabburn, Prof. Mary O'Brien, Prof. Barbara Jack and Dr. Kate Knighting  
Email: [clabburn@edgehill.ac.uk](mailto:clabburn@edgehill.ac.uk)

Please initial box

1. I confirm that I have read and understand the Information Sheet (Phase 3, Parent Information Sheet, Version 3, 15 January 2016) for the above study	
2. I understand that RecordMeNow is independent and can be used without having to participate in this research. Any messages made using RecordMeNow will stay private to me and my family and will not be accessible to the research team.	
3. I confirm that I have explained the study to my child and that we have had the opportunity to ask questions.	
4. I agree for my child to participate in this study if they want to. I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, without their legal rights being affected.	
5. I understand that the interview my child takes part in will be audio-recorded with their permission and will form part of the data collection for this study.	
6. I understand that the interview will be typed up and stored by the research team to form part of the data collection for this study. I agree for this to happen.	
7. I understand that some of the things my child says during the interview may be used in the final report and any publications. I understand that this will be anonymised.	
8. I understand that data collected during the study from my child may be looked at by the research team. I give permission for these individuals to have access to the records.	
9. I understand that some anonymised data extracts may be used by the research team as material for training purposes.	
10. I agree to for my child to take part in the above study if they want to.	

**Please turn over**

Investigating the use of a digital legacy with people affected by MND  
Participant ID Number:

Phase 3, Parental Consent Form for participants under 16, Version 3, 15 June 2016

I have read the 'Parental Consent Form for Participants under 16' and agree to providing consent for my child to participate in the research.

*Please complete the following*

Name of Child:

\_\_\_\_\_

Name of Parent/guardian:

\_\_\_\_\_

Signature:

\_\_\_\_\_

Date:

\_\_\_\_\_

Address:

\_\_\_\_\_  
\_\_\_\_\_

Country:

\_\_\_\_\_

Post/Zip code:

\_\_\_\_\_

Name of Researcher:

\_\_\_\_\_

Signature:

\_\_\_\_\_

Date:

\_\_\_\_\_

Investigating the use of a digital legacy with people affected by MND  
Participant ID Number:

Phase 3, Parental Consent Form for participants under 16, Version 3, 15 June 2016

*Appendix 8- An example of participant consent sheet (plwMND)*



Edge Hill University

**Participant Consent Form**

**Phase 1: Investigating the feasibility and experiences of people diagnosed with Motor Neurone Disease (MND) creating a digital legacy.**

Research Team: Olly Clabburn, Prof. Mary O'Brien, Prof. Barbara Jack and Dr. Kate Knighting

Email: clabburo@edgehill.ac.uk

Please initial box

1. I confirm that I have read and understand the Information Sheet (Phase 1, Participant Information Sheet, Version 3, 15 January 2016) for the above study and have had the opportunity to ask questions.	
2. (If applicable) I understand that RecordMeNow is independent and can be used without having to participate in this research. Any messages made using RecordMeNow will stay private to me and my family and will not be accessible to the research team.	
3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
4. I understand that the interview will be audio-recorded and will form part of the data collection for this study.	
5. I understand that the interview will be typed up and stored by the researcher to form part of the data collection for this study. I agree for this to happen.	
6. I understand that some of the things that I say during the interview may be used in the final report and any future publications. I understand that this will be anonymised.	
7. I understand that data collected during the study may be looked at by individuals from the researcher's supervisory team. I give permission for these individuals to have access to the records.	
8. I understand that some anonymised data extracts may be used by the research team as material for training purposes.	
9. I agree to take part in the above study.	



I have read the 'Participant Consent Form' and agree to providing consent for my participation in the research.

*Please complete the following*

Name of Participant:	Signature:	Date:
_____	_____	_____

Address:

\_\_\_\_\_

\_\_\_\_\_

Country:	Post/Zip code:
_____	_____

Name of Researcher:	Signature:	Date:
_____	_____	_____



## EPRC safe fieldwork protocol

### Guidance for the safe working and support for researchers conducting fieldwork

#### 1. Introduction

Staff in the Evidence-based Practice Research Centre conduct fieldwork across a variety of settings off-campus, including interviewing participants in their own homes. Staff will spend time working out in the community, often working alone. This fieldwork protocol aims to clarify the roles and responsibilities of the EPRC and its employees for the safety of staff working alone in the community.

This protocol is intended to minimise risks to staff while encouraging staff to take responsibility for their safety. It is recognised that staff working alone in the community are potentially at risk and that these risks must be minimised.

Safety concerns include:

- Safety on the streets and using public transport
- Car safety
- Working after dark/out of hours
- Working alone
- Distressing visits
- Aggressive or agitated behaviour (not generally expected in this fieldwork)

#### 2. Responsibilities and organisation

##### *The Director of the EPRC*

The Director has overall responsibility for the safety and support of all EPRC staff. The Director will work with the Principal Investigators to ensure that all staff have adequate resources to do their job safely, for example mobile phones, personal alarms, or pagers.

##### *Principal Investigator/Head of Department*

The PI or HoD will ensure that all staff follow the agreed protocol for safe working and will respond to any problems reported by staff conducting research fieldwork.

##### *All staff*

- All staff conducting fieldwork will follow the guidance as set out in this protocol and report any problems or concerns about the work or their safety to their PI or HoD.
- Where any resources are supplied it is the responsibility of the individual to maintain them in good working order.
- All members of staff should carry their mobile phone and ensure it is charged and switched on.
- It is the responsibility of each staff member to ensure to ensure their safety, inform people of their whereabouts, and withdraw from situations where they feel at an unacceptable level of risk.

#### 3. Buddy support system

The EPRC operates a buddy system for fieldwork for two reasons:

- *Safety:* The nominated buddy is the contact during out-of-office hours or when the Administrator is not available for notifying arrival and completion of fieldwork visits.
- *Support:* In addition to safety reporting, researchers will also have the opportunity to talk about the visit with a colleague.

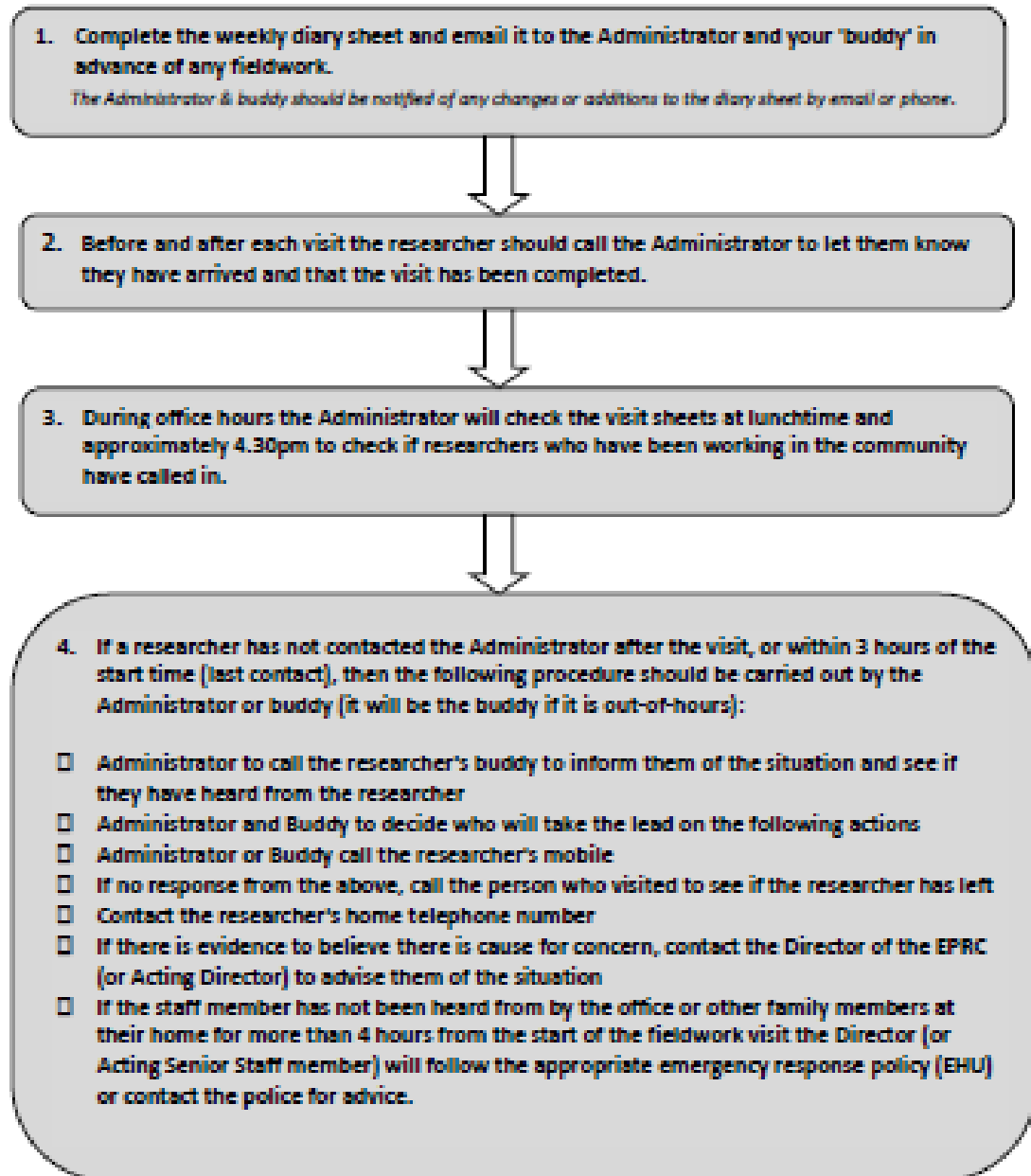
The buddy for Research Assistants will typically be the PI or a senior member of the project team. The Administrator will hold a list of researchers and their nominated buddies.

#### 4. Reporting concerns or problems

If a researcher has any concerns about a visit they should contact the PI as soon as possible to discuss the situation, and decide whether any action is needed. If further advice is needed the PI will contact the EPRC Director or recommend the researcher does so. During periods where the Director or PI are away (i.e. on annual leave or at a conference) the most senior member of the EPRC will act in this capacity.

Regular reviews of the protocol and safety concerns will be discussed at project meetings, and if necessary the EPRC team meeting, in order to reflect on the situation and share learning with the team.

#### FLOWCHART



Date protocol approved: Jan 2014

Date of next review: Jan 2015 – but pending due to EHU lone worker policy currently in development by UREC.

# **WEEKLY FIELDWORK SCHEDULE**

Researcher: Oliver Clabburn .....MOBILE 08800 880880 .....HOME TEL: 01100 110110 .....  
 Buddy: Supervisor's name .....MOBILE 09900 990990 .....HOME TEL: 02200 220220 .....

Please add date and brief name of project	Called/ Text arrived	Time of visit	Person's name	Full Address & Phone Number	Called/ Text completed
<b>Monday</b>					
Digital legacy study	<input checked="" type="checkbox"/>	10.30	John Smith	123 Pseudo Street, Bishops Fakeson, Madeupshire. 07700 770770	<input checked="" type="checkbox"/>
	<input type="checkbox"/>				<input type="checkbox"/>
<b>Tuesday</b>					
	<input type="checkbox"/>				<input type="checkbox"/>
	<input type="checkbox"/>				<input type="checkbox"/>
<b>Wednesday</b>					
	<input type="checkbox"/>				<input type="checkbox"/>
	<input type="checkbox"/>				<input type="checkbox"/>
<b>Thursday</b>					
	<input type="checkbox"/>				<input type="checkbox"/>
	<input type="checkbox"/>				<input type="checkbox"/>
<b>Friday</b>					
	<input type="checkbox"/>				<input type="checkbox"/>
	<input type="checkbox"/>				<input type="checkbox"/>

*Appendix 10- Motor Neurone Disease- Legacy Research (Facebook page)*

Olly
Home

Page
Messages
Notifications
Insights
Publishing Tools

# Edge Hill University

## Motor Neurone Disease- Legacy Research Community

Add a Button
Like
Message
...

Home
About
Photos
Events
More

Community

90% response rate, 6-days response time  
Respond faster to turn on the badge

326 likes +1 this week  
Mike Broadbridge and 59 other friends

See Pages Feed  
Posts from Pages you've liked as your Page

Invite friends to like this Page

Boost Your Page for £3  
Reach even more people in United Kingdom  
Promote Page

Status
 Photo / Video
 Offer, Event +

Write something...

**Motor Neurone Disease- Legacy Research**  
May 14, 2015 ·

My name is Olly and I'm currently a PhD Researcher at Edge Hill University in Ormskirk, Lancashire. I have a specific research interest in young people who help care for family members who have MND, and also those young people who are bereaved due to the disease. I have also been through the journey myself and so I am extremely passionate about supporting other children and young people who are currently in a similar situation.

My research is investigating the use of a digit...

[Continue Reading](#)

## Appendix 11- Twitter profile



The image shows a screenshot of a Twitter profile for Olly Clabburn. The profile picture is a circular portrait of a man with short brown hair, smiling. The background banner image shows a wide, sandy beach with waves crashing against a rocky shore under a cloudy sky. The profile information includes the name 'Olly Clabburn', the handle '@olly\_clabburn', a bio stating he is a PhD researcher looking at people with #MND and #ALS, recording video legacies for children, and research around #youngcarers, his location 'Somerset/Lancashire', his website 'facebook.com/mndlegacy', and that he joined in January 2015. It also shows 77 photos and videos. The stats bar indicates 563 tweets, 1,263 following, 703 followers, and 258 likes. A 'Follow' button is visible. The main content area shows two tweets. The first is a retweet from Shirley Potts (@shirleypotts) dated Nov 16, about Children's Grief Awareness Week. The second is a retweet from The Guardian (@guardian) dated Nov 17, featuring a video titled 'A child's grief: you have to acknowledge that something's happened' with a thumbnail showing a child's hand on a wooden surface. The video player has 'theguardianopinions' overlaid. The right sidebar contains a 'New to Twitter?' sign-up prompt, a 'You may also like' section with five suggested accounts (SWWalesMND, Lee Millard, Julie Sala, Clare Brennan, Stamp Out MND), and a 'Worldwide trends' section showing a hashtag in Arabic.

**Olly Clabburn**  
@olly\_clabburn

PhD researcher looking at people with #MND #ALS recording a video legacy for children in their family #mndlegacy. Research also around #youngcarers.

📍 Somerset/Lancashire  
🌐 facebook.com/mndlegacy  
📅 Joined January 2015  
📷 77 Photos and videos

Tweets 563 Following 1,263 Followers 703 Likes 258 [Follow](#)

**Tweets** Tweets & replies Media

Olly Clabburn Retweeted  
**Shirley Potts** @shirleypotts · Nov 16  
16-22 Nov is #ChildrensGriefAwareness Week: a chance to remind bereaved children & young people #YoureNotAlone [instagram.com/p/8bbwCr6Dw7X/](https://www.instagram.com/p/8bbwCr6Dw7X/) via @

Olly Clabburn Retweeted  
**The Guardian** @guardian · Nov 17  
A child's grief: you have to acknowledge that something's happened

**the guardian opinions**

A child's grief: you have to acknowledge that something's happened  
As part of children's grief awareness week, the staff who support families caring for terminally ill children on the need to be honest and consistent

**New to Twitter?**  
Sign up now to get your own personalized timeline!  
[Sign up](#)

**You may also like** · Refresh

- SWWalesMND** @SWWalesMND
- Lee Millard** @Onein400
- Julie Sala** @sala650
- Clare Brennan** @mndaeditor
- Stamp Out MND** @StampOutMND

**Worldwide trends**  
#امطارالرياحي 31K Tweets



**Interested in participating in research?**

My name is Olly and I'm a PhD researcher looking at the use of a 'digital legacy' with people affected by MND/ALS.

This means people with MND/ALS create a series of videos with memories and messages, specifically to be given to a child or young person in their family.

I am interviewing people face-to-face or via Skype about their experiences. I am keen to hear from people who:

Have MND and are interested in recording/have recorded a digital legacy for a young person in their family.

Are young people (aged 11-24) who currently help to care for someone with MND and use a pre-recorded digital legacy as a means of support.

Are young people (aged 11-24) who have lost a family member who had MND and use a pre-recorded digital legacy to support them as they grieve.





Edge Hill University

For more information:

 [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk)

 [facebook.com/mndlegacy](https://facebook.com/mndlegacy)

 01695 654316



Are you aged 11-24?

Have you lost a family member that had MND?

Do you have special videos or DVD's of the  
person?

*I'm interested in hearing about young people's  
experiences of watching videos or DVD's to help with  
your loss and would love to hear from you.*

For more information, please email  
[clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk)



## Appendix 13- Example of a forum post



Committed to providing a site that is safe for everyone affected by motor neurone disease (MND).

[Watched Topics](#) [FAQ](#) [Search](#) [Memberlist](#) [Usergroups](#) [Register](#)  
[Profile](#) [Log in to check your private messages](#) [Log in](#)

### Research request: recording memories & messages for chil

[newtopic](#)

[postreply](#)

[Build-UK Chat Forums Forum Index -> MND related discussion](#)

[View previous topic :: View next topic](#)

Author

Message

**Olly2015**

New Member

Joined: 07 Oct 2015  
Posts: 4  
Location: Lancashire

Posted: Wed Oct 07, 2015 9:46 am Post subject: Research request: recording memories & messages for chil

[quote](#)

Hello everybody,

My name is Olly and I'm currently a PhD Researcher at Edge Hill University in Ormskirk, Lancashire (UK). I have a specific research interest in young people who help care for family members who have MND, and also those young people who are bereaved due to the disease. I have also been through the journey myself and so I am extremely passionate about supporting other children and young people who are currently in a similar situation.

My research will be investigating the use of a digital legacy for people affected by MND. This means video-recording memories, accomplishments and messages specifically for use by children in the person's family.

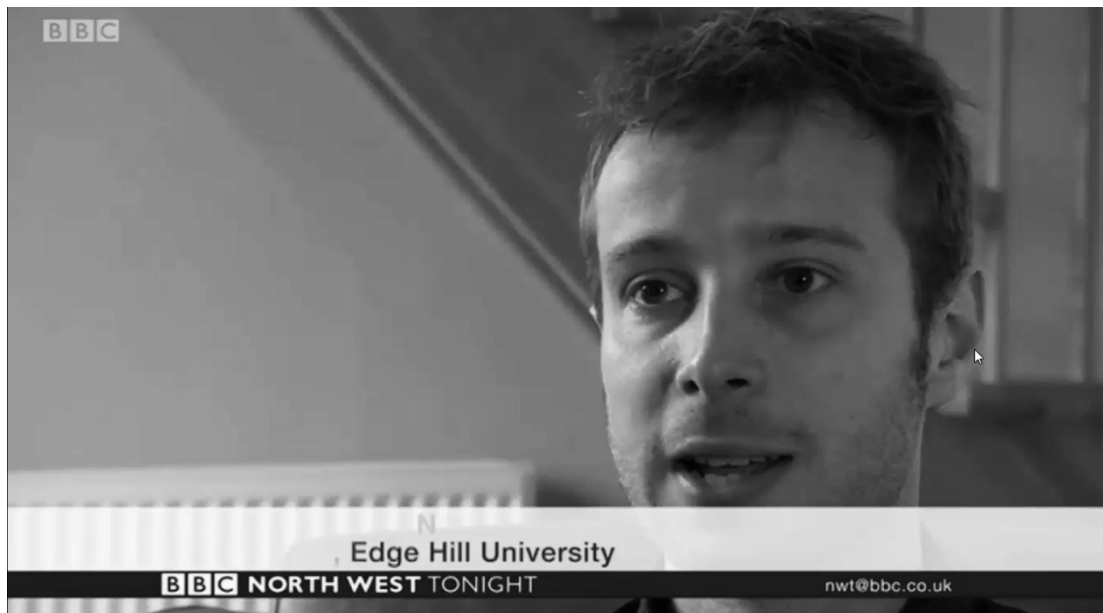
I am planning to interview three groups of people:

- 1 > People who have been diagnosed with MND and are recording/have recorded a digital legacy for a child or young person in their family (e.g. son/daughter/grandchild/niece/nephew)
- 2 > Young people (aged 11-24) who currently care for a family member with MND and use a pre-recorded digital legacy as a means of support.
- 3 > Young people (aged 11-24) who are bereaved due to losing a family member who had MND using a pre-recorded digital legacy to support them whilst they grieve.

I am aiming to interview around 10 people from each group to investigate their thoughts, views and experiences of being affected by MND and creating or using a digital legacy. Interviews can be carried out face-to-face or via Skype depending on your location and will be informal making it feel more like a conversation lasting around 20-30 minutes.

For more information, please email me via [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk) or have a look at my research page [www.facebook.com/mndlegacy](http://www.facebook.com/mndlegacy)

*Appendix 14- BBC North West Tonight interview (consent obtained for use)*



Appendix 15- Newspaper article for Lancashire Evening Post  
(<http://bit.ly/1rlEVBo>)

LANCASHIRE

Evening Post

NEWS

TRANSPORT

CRIME

EDUCATION

BUSINESS

POLITICS

ENVIRONMENT

HEALTH

YOUR SAY

MORE

COMPENSATION CLAIMS

You have ONE CHANCE to claim!

CLAIM NOW

Talk to tollers

tollers

personal injury

## Olly's very personal quest to help others hear their parents' voice



Olly Clabburn as a child with his dad who died of Motor Neurone Disease

By  
**AASMA DAY**

Published: 18:24 Friday 10 June 2016

f

t

g+

e

Repeatedly pressing **play** on the telephone answering machine, a young Olly Clabburn listened avidly to the crackly message of his father's voice.

Olly, now 26, explains: "In the mid-nineties, my family joined the **technology** revolution with an answering machine.


0

comments

HAVE YOUR SAY


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Culture Amp



POST OFFICE

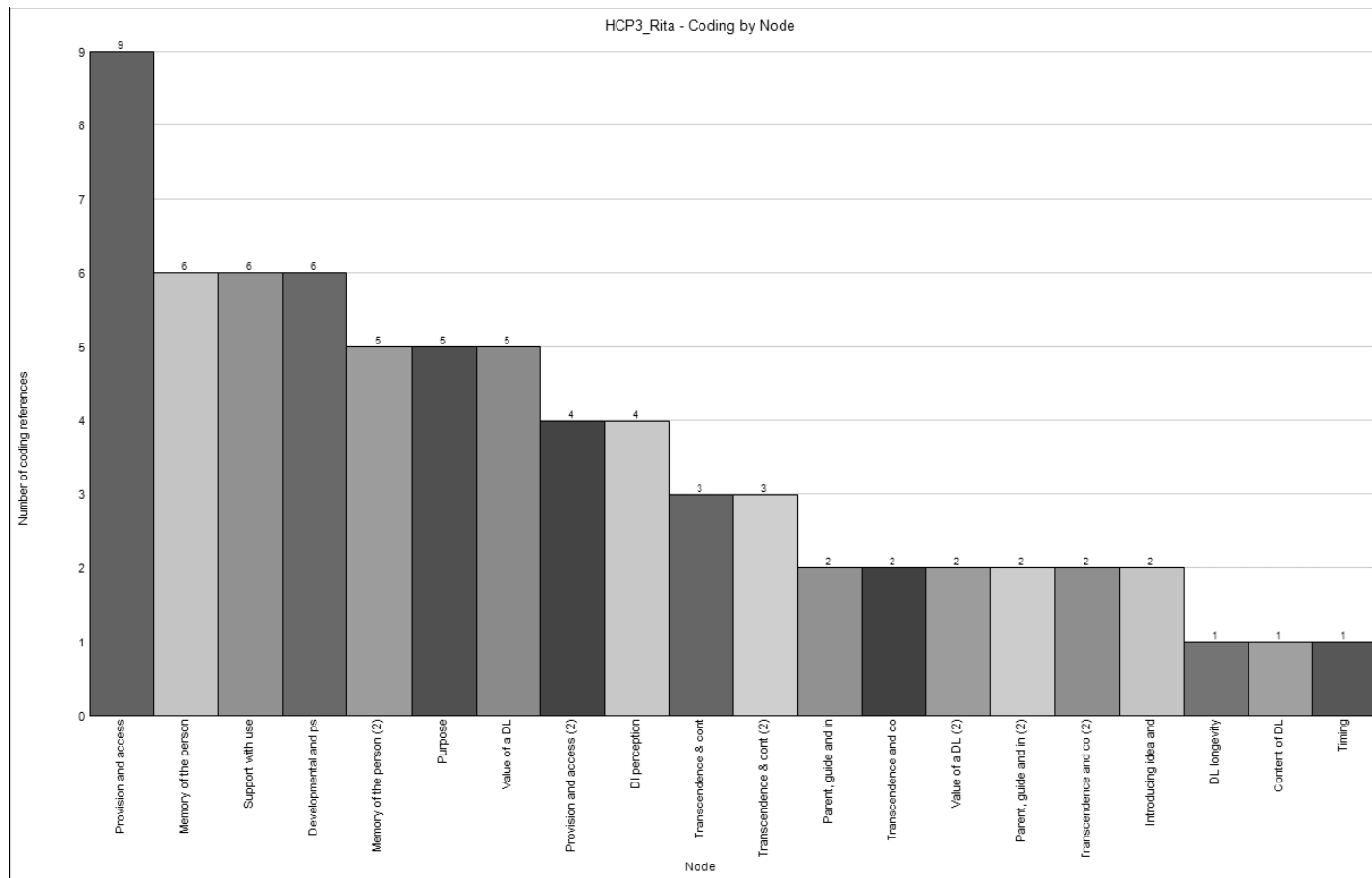
Order online now



\*Orders between £400 & £2500 only

380

## Appendix 16- An example of an NVivo report for frequency of codes



## Appendix 17- An example of participant quotes compiled into theme

Name: Psychological challenges of creating DL

<Internals\HCP1\_Kim> - § 2 references coded [5.63% Coverage]

Reference 1 - 3.11% Coverage

I think there's the challenge of feeling completely overwhelmed by it, often people will know that they want to do something, but then keep putting it off because it's too big.

I        yeah

P        or it's too emotive or, it sort of gives them a feeling that it'll bring things forward, almost as if it's superstitious to do it

Reference 2 - 2.52% Coverage

P        yeah, and it's too late sometimes. And often some people will not think about it until it's too late and then they're not able for it. So we then have to think about, simple things like handprints, so that they can actually leave something for a youngster

<Internals\HCP10\_Kirsty> - § 3 references coded [4.75% Coverage]

Reference 1 - 2.54% Coverage

she was also sort of putting it off at the same time, or I mean wanting to do it, but wanting it to be the right time and blocking us. And we were getting very anxious that it was going to be too late

I        why do you think she was blocking it then?

HCP10 I don't know. Maybe it was, maybe she knew she'd get very emotional about it and find it very painful so although it's something she was really important to her and really wanted to do, I think actually, the actual sitting down and doing of it, she was almost worried about and frightened of what, she was just finding that really difficult.

Reference 2 - 1.61% Coverage

I        what about patients?

HCP10 yeah I think as I mentioned with the case I was thinking, I guess it could be, particularly with video recordings, I guess if a patient has, worries of body image with how they look, how they sound. That might be quite difficult for them. So both voice recording or visual recording, so that might be something that they need to be supported with

Reference 3 - 0.60% Coverage

HCP10 yes I guess it is how you want to be remembered and some people don't want to be remembered in their ill phase so that might deter them

<Internals\HCP11\_Sue> - § 7 references coded [8.71% Coverage]

Reference 1 - 1.02% Coverage

it's about getting under barriers that people have. The easy way, it's not always easy. The aim of it is to make it really easy, that people don't encounter any fears or, do you know what I mean? That it doesn't make people feel anxious or can't do it

Reference 2 - 1.56% Coverage

you want to make it really simple for people to achieve something, that they're confidence then goes with that. That they don't feel 'I'm going to fail'. And if it's something they don't want to do then that's fine, you're not here to force that. If they want to have a go, it's about making that as simple and as painless a process, and you want to engage them in the excitement of it

Reference 3 - 0.50% Coverage

HCP11 yes, in terms of what they've lost, and so on. Again it's about letting people talk about what comes really, isn't it?

Reference 4 - 1.17% Coverage

Obviously it is challenging because people are in a difficult place where they've had no experience necessarily of how to deal with this point, and the sense that their awareness of things hasn't changed but their physical ability to deal with things has changed, that is a big challenge.

Reference 5 - 0.49% Coverage

HCP11 it's projecting forward isn't it, to think about what you think your child will need, what guidance they will need

Reference 6 - 3.23% Coverage

HCP11 I think the biggest thing is going back to this thing of being in the moment. It's about using what you have right now to the best of your ability to the best of your ability to record something on the basis that you won't, you have to grab this moment, it is about grabbing this moment and doing what you can, what you feel inspired to do and what you want to do, with your loved ones in mind. It's about doing what you can do, here and now, don't make it too complicated that you can't achieve it. It's about grabbing what you have around you, your phone or whatever, doing a recording and getting it now, because you don't know. Next week, if you have an opportunity next week you may not feel the same as you do now, physically. You have to work in the moment to the best of your ability


Reference 7 - 0.74% Coverage

HCP11 yes, so make it simple. Because if it's too complicated people's minds will put up barriers why they can't do it, because it seems unachievable. It's about here and now [laugh]

<Internals\HCP12\_Rose> - § 2 references coded [3.45% Coverage]

Reference 1 - 0.62% Coverage

## Appendix 18- An example of the information provided on Facebook and responses



**Motor Neurone Disease- Legacy Research**

May 14, 2015 · 🌐

My name is Olly and I'm currently a PhD Student at Edge Hill University in Ormskirk, Lancashire. I'm carrying out a piece of research investigating the experiences of people affected by Motor Neuron Disease (MND) who record video messages for their children.

I have a specific research interest in young people who help care for family members who have MND, and also those who are bereaved due to the disease. Not only this, but I have been through the journey myself and so I am extremely passionate about supporting other children and young people who are currently in this situation.

I am investigating the use of digital legacies with people affected by MND. A 'digital legacy' is a selection of videos that have been purposefully recorded for a child or young person in your family. This is unique to each person with some people recording things like bed-time stories, discussing items in a memory box, or perhaps more structured videos about their life, memories and achievements.

My research is focussed upon the experiences of people affected by MND either creating, or using, a digital legacy. I am interested in hearing from two groups of people who:

>Are living with MND and have created a digital legacy for a child or young person in their family


OR

>Are a bereaved young person (aged 11-24yrs) who use videos as a method of support (e.g. home-movies or purposefully recorded videos)


I am interested in hearing about their thoughts, views and experiences of being affected by MND and creating/using a digital legacy. This will be through an informal interview lasting for around 30mins either face-to-face or via Skype (depending on preference).

If you are interested in participating in the study or have any additional questions, please get in touch directly through this Facebook page, via telephone (01695 654316), or email [clabburo@edgehill.ac.uk](mailto:clabburo@edgehill.ac.uk).

31 Shares
7 Comments




Write a comment...



Hello Olly, I will share your article on the Social Embers Facebook page and put a link in my weekly newsletter that is published on Friday.


1

Like · Reply · Message · 1y



Motor Neurone Disease- Legacy Research Brilliant, thank you ever so much!


Like · Reply · 1y



Hi I've just finished record me now and have banked my voice. \*\*\* feel free to contact me if i can help


1

Like · Reply · See Response · 1y




Motor Neurone Disease- Legacy Research Hi Dean, sound's great, I will send you a private message now.

Like · Reply · 1y




I have included a link to your page in our Norwich and Waveney Branch newsletter. Thank you for the work you are doing.

Like · Reply · Message · 1y



Motor Neurone Disease- Legacy Research Fantastic, thank you Sue!

Like · Reply · 1y



Hi Olly. Someone I know has just shared your page into my local MND branch so I just thought I'd comment saying I'm currently a student at Edge Hill University, just finished my first year. I've been involved in fundraising and volunteering for the MND... See More

2

Like · Reply · Message · 2y

Appendix 19- Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist (Tong, Sainsbury and Craig, 2007)

No. Item	Guide questions	Outcome	Reported in section(s)
<b>Domain 1: Research team and reflexivity</b>			
<i>Personal Characteristics</i>			
1. Interviewer/facilitator	Which author/s conducted the interview or focus group?	OC conducted all interviews	<u>Methods</u> (Chapter 5)
2. Credentials	What were the researcher's credentials? E.g. PhD, MD	Study conducted for PhD	<u>Title page</u>
3. Occupation	What was their occupation at the time of the study?	PhD Student	<u>Title page</u>
4. Gender	Was the researcher male or female?	Male (evident from name)	<u>Title page</u>
5. Experience and training	What experience or training did the researcher have?	Ongoing throughout the study due to being a PhD	<u>Title page</u>
<i>Relationship with participants</i>			
6. Relationship established	Was a relationship established prior to study commencement?	No previous relationship. Rapport was built through initial conversations with participants	<u>Methods</u> (Chapter 5)
7. Participant knowledge of the interviewer	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	Participants knew of OC's personal experience and interest in research topic	<u>Methods</u> (Chapter 5)
8. Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	OC's personal experience was clearly described	<u>Preface</u> <u>Reflexive chapter</u> (Chapter 10)

Domain 2: study design			
<i>Theoretical framework</i>			
9. Methodological orientation and Theory	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	Interpretative Phenomenological Analysis (IPA) provided methodological underpinning	<u>Methodology</u> (Chapter 4)
<i>Participant selection</i>			
10. Sampling	How were participants selected? e.g. purposive, convenience, consecutive, snowball	Self-selected, purposive sample	<u>Methods</u> (Chapter 5)
11. Method of approach	How were participants approached? e.g. face-to-face, telephone, mail, email	Online and offline methods of recruitment	<u>Methods</u> (Chapter 5)
12. Sample size	How many participants were in the study?	4 plwMND 3 bereaved young people 20 healthcare professionals, specialists and experts	<u>Findings</u> (Chapters 6, 7 & 8)
13. Non-participation	How many people refused to participate or dropped out? Reasons?	Refusal to participate unknown due to method of recruitment	<u>Findings</u> (Chapters 6, 7 & 8)
<i>Setting</i>			
14. Setting of data collection	Where was the data collected? e.g. home, clinic, workplace	Home, place of work and telephone	<u>Findings</u> (Chapters 6, 7 & 8)
15. Presence of non-participants	Was anyone else present besides the participants and researchers?	One plwMND interviewed with wife present (Tommy) Two child bereavement therapists interviewed together (Jess & Kacey)	<u>Findings</u> (Chapter 6)  (Chapter 8)



16. Description of sample	What are the important characteristics of the sample? e.g. demographic data, date	Summaries of participant demographic data presented in tables within each findings chapter	<u>Findings</u> (Chapters 6, 7 & 8)
<i>Data collection</i>			
17. Interview guide	Were questions, prompts, guides provided by the authors?	A prompt sheet was used during interviews	<u>Methods</u> (Chapter 5)
18. Repeat interviews	Were repeat inter views carried out? If yes, how many?	One repeat interview was conducted with John	<u>Findings</u> (Chapter 6)
19. Audio/visual recording	Did the research use audio or visual recording to collect the data?	Interviews were audio recorded	<u>Methods</u> (Chapter 5)
20. Field notes	Were field notes made during and/or after the interview or focus group?	Reflective notes were made following each interview in a journal	<u>Methods</u> (Chapter 5)
21. Duration	What was the duration of the inter views or focus group?	Mean duration of interviews stated at the beginning of each findings chapter	<u>Findings</u> (Chapters 6, 7 & 8)
22. Data saturation	Was data saturation discussed?	Themes based upon overall consensus	<u>Findings</u> (Chapters 6, 7 & 8)
23. Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No, not in accordance with methodology. Independent auditing conducted with members of supervisory team	<u>Methods</u> (Chapter 5)

Domain 3: analysis and findings			
<i>Data analysis</i>			
24. Number of data coders	How many data coders coded the data?	Data coded by OC with supervisors as independent auditors	<u>Methods</u> (Chapter 5)
25. Description of the coding tree	Did authors provide a description of the coding tree?	An overview of themes provided at the beginning of each findings chapter	<u>Findings</u> (Chapters 6, 7 & 8)
26. Derivation of themes	Were themes identified in advance or derived from the data?	Themes were derived from the data	<u>Methods</u> (Chapter 5) <u>Findings</u> (Chapters 6, 7 & 8)
27. Software	What software, if applicable, was used to manage the data?	Data was analysed using NVivo	<u>Methods</u> (Chapter 5)
28. Participant checking	Did participants provide feedback on the findings?	No, not in accordance with methodology	<u>Methods</u> (Chapter 5)
<i>Reporting</i>			
29. Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	Participant quotes were provided to contextualise all themes with inclusion of pseudonym's	<u>Findings</u> (Chapters 6, 7 & 8)
30. Data and findings consistent	Was there consistency between the data presented and the findings?	Findings were contextualised between other findings chapters and later related to existing literature	<u>Findings</u> (Chapters 6, 7 & 8) <u>Discussion</u> (Chapter 9)

31. Clarity of major themes	Were major themes clearly presented in the findings?	Major themes were discussed and synthesised with existing literature	<u>Findings</u> (Chapters 6, 7 & 8) <u>Discussion</u> (Chapter 9)
32. Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Minor themes were discussed and synthesised with existing literature	<u>Findings</u> (Chapters 6, 7 & 8) <u>Discussion</u> (Chapter 9)